The use of Internet-based communication by people with autism

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ABSTRACT

Despite having difficulties in the areas of social interaction and communication, the introduction of the Internet seems to have encouraged some high-functioning autistic people to communicate with each other via chat rooms and bulletin boards. The Internet can address the social isolation of autism by improving the potential to find others who have similar experiences. Additionally it may be that, for autistic people, the Internet also offers a comfortable space more suited to their communication style, perhaps one in which their interaction seems less odd. If so, there are possible implications for this group of people in terms of education, employment and social inclusion. However there are risks. Autistic people may be particularly vulnerable to individuals misrepresenting themselves or to the possibility of over-reliance on computer-mediated interaction resulting in an exacerbation of obsessive behaviour and withdrawal from face-to-face interaction. An initial survey, to discover the extent of Internet use among people with autism and investigate their motivations for using it, was carried out, obtaining responses from 138 people with high-functioning autism or Asperger syndrome. Results indicated a high level of computer and Internet use amongst respondents and implied that email was a popular means of communication, more so than face-to-face communication even when interacting with friends. This introductory survey raised issues and questions which were explored in more depth with a subset of the respondents who were interviewed by email about their experiences, motivations and perceptions regarding Internet-based communication. In addition to 19 email interviews, data were also collected from 4 non or reluctant users of the Internet who were sent a series of questions by post. A grounded theory analysis of the data revealed a heightened awareness of communication amongst this group of participants, who offered insights into the process of communication in terms of its component parts and how it breaks down for them. Central to the analysis is a theme of the interviewee as observer, feeling detached to some degree from mainstream interaction and like an outsider. From this perspective participants offered their analysis of the complex process of communication, online and offline as they experienced it, highlighting key aspects of the Internet in relation to their own needs, ones which made it a unique form of communication. Their insights into communication are described in four themes: control, clarity, the role of nonverbal communication and the social role of communication. Additionally the interviewees expressed a sense of liberation that could come with online communication for people with Asperger syndrome/high-functioning autism such that they may interact with others on a more equal basis. This could be empowering but with the sense of liberation there was a risk of losing control over one's interactions. The interviewees' perceptions of CMC are explored within a uses and gratifications framework which posits that people use particular communication channels to satisfy their individual needs and motives. By using computer-mediated communication some of the social and communication barriers which contribute to the disability of autism may be broken down.

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DEDICATION

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CHAPTER 1: INTRODUCTION

Background to the study

Autism affects an individual's social interaction, communication and imagination. Autistic people fall along a spectrum with, at one end, "high-functioning" individuals of normal or superior intelligence, often described as having Asperger syndrome. These people are highly verbal but have difficulty with nonverbal aspects of social communication, for example facial expression, gestures, eye contact, and tone of voice; aspects which modify meaning, convey emotion, provide indications of status and role, and support conversational turn taking and other aspects of communicative fluency. Other characteristics include an almost obsessive desire for sameness of environment and routine, unusually narrow and engrossing "special interests", difficulties processing and retaining verbal information and understanding non-literal language (jokes, sarcasm, turns of phrase), and peculiarities of attention and perception. The social impairment of autism is such that people at the high-functioning end of the autistic spectrum are often disadvantaged in terms of obtaining and sustaining employment (Barnard et al., 2001), particularly jobs commensurate with their intellectual strengths. They are at risk of social isolation, marginalisation, and psychological problems such as low self-esteem, stress, anxiety and depression (Attwood, 2003; Ghaziuddin, 2005). Because of their intelligence and, for some, the ability to hide their social impairment in straightforward situations, the needs of high-functioning autistic people may receive insufficient recognition (Frith, 2004). Additionally they are not easily accommodated or prioritised by existing support services (Macleod, 1999), although research indicates that the availability of a supportive social network (family, employment, social services) is an important determinant of quality of life for high-functioning autistic individuals (Renty & Roeyers, 2006). Hence their social exclusion may be compounded by an underestimation of their needs and a lack of appropriate support services.

Anecdotal reports indicate that the Internet has encouraged high-functioning autistic people to communicate with each other via chat rooms, bulletin boards and discussion lists (Blume, 1997b). The impact of the Internet on high-functioning autistic adults has been likened to that of sign language on the deaf

community (Blume, 1997b). It has also been credited with facilitating the emergence of autistic culture and self-advocacy, and being an essential means of communication by which autistic individuals may offer each other emotional and practical support (Dekker, 1999). However there is very little empirical research into the use of the Internet by people with autism.

Research into computer-mediated communication (CMC) more generally, indicates that there are implications of its use for interpersonal communication, relationships, and individual wellbeing. However this is a complex relationship, in which the effects of CMC are determined largely by the personal characteristics of participants, their goals and motivations, which in turn influence their communicative choices. There is evidence to suggest that, attracted by the lack of nonverbal feedback or social status cues, the potential anonymity and different pace of online communication, lonely or socially under-confident individuals are using the Internet to compensate for deficiencies in more traditional communication situations (Morahan-Martin & Schumacher, 2003; Papacharissi & Rubin, 2000; Recchiuti, 2003; Roberts et al., 2001). They are more likely to perceive the Internet as liberating, enabling self-expression and extending possibilities for the formation of new relationships (Morahan-Martin & Schumacher, 2003). The Internet may also be liberating for other groups of people who are socially excluded due to issues of disability (Guo et al., 2005) or stigma (McKenna & Bargh, 1998), enabling them to bypass physical, communication or attitudinal barriers (Guo et al., 2005; McKenna et al., 2002).

Studies of online communities dealing with a range of different issues (for example diabetes, depression, disability, alcoholism, chronic fatigue syndrome and bullying; see Burrows et al., 2000) conclude that computer-mediated social support can occur providing esteem support, informational support and social companionship. Central to this is a supportive peer group with shared needs and experiences. Additionally due to its potential to afford its users anonymity, flexibility and control, the Internet may offer a unique form of social support, complementing that which is available from personal networks or local resources.

Despite their difficulties with social interaction and communication, people with high-functioning autism are not necessarily loners by choice (Klin & Volkmar, 2000) and, being of normal intelligence, are often highly aware of their difficulties in social situations. The Internet can address the social isolation which many experience by enabling contact with a peer group which may not

otherwise occur for reasons of location. Additionally it may be that for autistic people the relatively predictable, slower, anonymous, text-based and single-channeled nature of the Internet offers a comfortable space in which to communicate, one which is more suited to their communicative style. It may enable them to bypass their struggles with nonverbal communication, and provide an anonymous and arguably safe environment in which to try out social skills and "shop around" for new social contacts.

However, along with opportunities for interaction the Internet also brings risks. Some people when online become disinhibited in their behaviour, and act in ways uncharacteristic of their offline behaviour (Suler, 2004). They may be more apt to deceive or use offensive or aggressive language towards others, or engage in illegal or socially unacceptable activities. The social impairment of autism is such that individuals with the disorder may be more susceptible to the deceptive behaviour of others online. There is also the risk that they may be disinhibited in their own behaviour, resulting in excessive and obsessive use of the Internet and the neglect of other aspects of their lives (Howlin, 1998). Some writers warn that rather than being a socially inclusive medium, the Internet may serve to further the segregation of marginalised groups (Seymour & Lupton, 2004).

Introducing the research question

Current literature on the use of CMC by autistic people is largely anecdotal or speculative, with very little existent empirical research. Consideration of this topic raises many interesting questions, for example, how does online communication by autistic people compare with neurotypical[1] people? Are they perceived as different online? How does online communication affect the psychosocial wellbeing of autistic people?

As this was a largely unresearched area it was decided to begin with an exploratory approach, and as such there were no predetermined hypotheses or narrowly focused research questions. To frame the study around such an approach would be to limit the potential for the emergence of the salient aspects of the research topic. Given the novelty of the subject under study, there was a drive toward obtaining some breadth of knowledge whilst at the same time investigating in more depth and detail the complexities of this aspect of social activity. The research question and associated aims and objectives were formulated on this basis:

[1] This term is used widely in the online autism community and was invented to refer to people without neurological conditions such as autism (Dekker, 1999)

How do people with high-functioning autism (HFA) or Asperger syndrome (AS) experience the Internet as a communication medium?

Aim 1

To explore the ways in which the Internet is being used for communication by people with HFA or AS

Objectives

- To find out how access to the Internet is obtained by people with AS or HFA
- To find out the amount of time being spent online by people with AS or HFA and the level of satisfaction with this quantity
- To place CMC use in the context of other forms of Internet use, computer use, social contact and communication
- To explore the reasons why people with AS or HFA use the Internet for communication

Aim 2

To explore the experiences, motivations and perceptions of people with HFA or AS who use the Internet for communication

This was a two stage project in which a combination of quantitative and qualitative approaches was used. An initial survey of adults with high-functioning autism or Asperger syndrome was carried out to address the first research aim. This provided contextual information regarding the use of the Internet for communication by this group of people. Additionally it identified issues pertaining to their motivations and perceptions regarding the Internet. These were explored in more depth in the second part of the study, in which a subset of the survey respondents was interviewed by email to address the second research aim. Data were also collected from a small number of non or reluctant users of the Internet, who responded to a series of open questions sent by post, as well as follow up questions based on their replies to the previous questions.

The present study would contribute to knowledge of the significance of the Internet to the autistic community. As well as exploring the implications of online communication for autistic people, it may aid understanding of the nature of autism itself. If the Internet is extending our concept of community

(Wellman, 2001), and if autistic communities are developing as part of this, can cyberspace provide a medium in which the cultural border between autistic and neurotypical communities can be crossed with implications perhaps for education, employment and social participation? This could be threatened, if future technological developments and commercial influences transform the Internet into a medium with less emphasis on the textual mode, one in which video streaming is commonplace, thereby diminishing those features of online communication which are possibly empowering to autistic users, but only tolerated by the neurotypical community.

If the Internet is enabling to high-functioning autistic communication and culture, then access and training should be a fundamental right (see the European Charter for Persons with Autism, which was adopted by the European Parliament in 1996;Autism-Europe, 1996)[2] and its potential to benefit less able autistic people should be considered.

The structure of the thesis

Chapters 2 and 3 of this thesis will present a comprehensive overview of the literature pertaining to the two subject areas encompassed by the research question: autistic spectrum disorders and computer-mediated communication. Together they provide the context from which the motivation for this piece of research evolved. Chapter 2 provides a detailed description of the features of autistic spectrum disorders, as well as current research and theory regarding their psychobiological and cognitive bases. There is particular emphasis on the psychosocial needs of those individuals at the high-functioning end of the spectrum, who are the focus of this study. The use of the terms high-functioning autism and Asperger syndrome are also discussed, as well as approaches to intervention for these more able individuals.

Chapter 3 provides an overview of the growth and ongoing development of the Internet, with particular emphasis on its capacity as a communication medium, and the psychosocial implications of the emergence of this vast and revolutionising technology. The chapter reviews research and theory pertaining to Internet-based communication with respect to interpersonal dynamics, social

[2] The following are particularly relevant:

- The right of people with autism to live independent and full lives to the limit of their potential.
- The right of people with autism to the equipment, assistance and support services necessary to live a fully productive life with dignity and independence
- The right of people with autism to participate in and benefit from culture, entertainment and sport
- The right of people with autism of equal access to and use of all facilities, services and activities in the community.

relationships, personal well-being, and the implications for the provision of counselling and for the needs of people with disabilities. The chapter finishes with an exploration of the potential role of Internet-based communication for people with autistic spectrum disorders, thereby setting the scene for this piece of research.

An account of the methodology employed to address the research question and aims is presented in Chapter 4. Consideration is given to issues of epistemology, ethics, feasibility and acceptability which inform the design of this study. The chapter begins with an exploration of the paradigmatic assumptions which guided the approach to data collection and analysis, and then explicate the details of the research design and procedure. Discussion of the methods employed in this piece of research is contextualised, with particular consideration to the target population and the medium used for the collection of data.

The findings of the first part of the study, the survey which addresses the first research aim, are presented in Chapter 5, and their implications are discussed in Chapter 6. The findings are considered in the context of relevant research and literature, as well as the methods of data collection used. The chapter is structured around the four objectives which were set to fulfill the research aim, and concludes with a series of issues generated by the analysis and discussion, which were pursued in the second, interview stage of the study.

Chapter 7 presents the themes which emerged from a grounded theory analysis of the interview data, and includes extracts from the interviews as illustrations of the interpretations made. These findings are explored in Chapter 8, in relation to relevant research and theoretical models from the fields of autism and computer-mediated communication, in particular the uses and gratifications perspective which proposes that the use of a particular communication channel is guided by the drive to satisfy individual needs and motivations (Caplan et al., 2007). This chapter also includes a discussion of the methodology used in terms of the implications for the interpretation of the research findings, as well as reflections on the experience of using the Internet as a communication medium in which to interact and interview this group of people. The chapter finishes by considering the wider implications of this piece of research for people with autism, and their families and carers, as well as relevant service providers and professionals. Future research directions which could be pursued in the light of this exploratory study are also discussed.

CHAPTER 2: AUTISTIC SPECTRUM DISORDERS

Historical context

The label autism (from the Greek *autos* meaning self) was introduced by the psychiatrist Eugen Bleuler, in 1911, to describe the "withdrawal from the fabric of social life into oneself" characteristic of schizophrenia. The term was then used by Leo Kanner (1943) and Hans Asperger (1991 [1944]) almost simultaneously although independently of each other in the 1940s, to describe the disorder as it is known today. Both described groups of children characterised by a propensity for narrow, repetitive behaviours and routines, as well as difficulties with social relationships and communication.

According to Frith (2004), Asperger's description of the disorder was much wider than Kanner's, from cases with severely impaired functioning to those on the borderlines of normality. However, the term Asperger (or Asperger's) syndrome, introduced by Lorna Wing (1981), has come to be used as a label for the highly verbal autistic person of normal intelligence (Tantam, 1988), whilst the term autism is associated with the socially passive, aloof, silent individuals described by Kanner, amongst whom there is a high incidence of global learning disability (Fombonne, 1999). There is considerable debate as to whether or not people with Asperger syndrome constitute a "high-functioning" subgroup of autism, or whether the two can be seen as distinct disorders.

The prevalence of autism is reported to be increasing, but it is not clear whether this increase is apparent, due to broadening diagnostic criteria as well as improved understanding and awareness of the condition, rather than real as a result of external factors. Current estimates of the prevalence of autism in children offer figures of around 1 in 100, from which the UK National Autistic Society (NAS) extrapolate the UK population of people with autism to be over 500,000 (National Autistic Society, 2007). The authors of one such prevalence study, of 9-10 year olds in the South Thames region of the UK, regard this as a minimum figure, due to difficulties identifying children with Asperger syndrome or high-functioning autism (Baird et al., 2006). Estimates of the proportion of individuals with an associated learning disability vary, but the NAS regard it as likely that more than 50% of those with autism have an average to high IQ (National Autistic Society, 2007).

The features of autistic spectrum disorders

Autism was first accepted as an official diagnosis in 1980 (American Psychiatric Association, 1980). Current diagnostic systems including DSM-IV-TR (American Psychiatric Association, 2000) and ICD-10 (World Health Organization, 1993) view autism as a spectrum of disorders characterised by four core features present in varying degrees. These are impairments of social interaction, communication and imagination (the triad of impairments as defined by Wing & Gould, 1979) and a markedly restricted repetitive and stereotyped repertoire of behaviour, activities and interests. Although treated as separate criteria, it will be evident from the discussion below that these features interrelate and overlap, for example impairments of imagination have implications for the ability to see another person's perspective, thus influencing social empathy, a crucial element of social communication and interaction

The core features of autistic spectrum disorders

Impairments of social interaction

Wing (1992) describes four types of behaviour which characterise the difficulties engaging in two way personal interactions experienced by people with autism: aloof, passive, odd and over-formal stilted. Individuals will tend to be categorised by the predominating behaviour type, but may exhibit all types depending on the situation.

The aloof individual is unresponsive and uninterested in their peers, seeming cut off and completely absorbed in their own world. There is a profound lack of eye contact or facial expression, except in moments of intense emotion.

Passive behaviour is characterised by indifference to social contact which is tolerated but not initiated. Individuals are compliant and risk being "led astray" by their peers. Eye contact is poor but they are amenable to reminders to look at other people.

The odd type of behaviour is characterised by apparent desire to interact with other people, confounded by a lack of awareness of the appropriate way in which to do this. Such individuals may be over-exuberant in terms of physical contact, or talk at length about their own interests in a peculiar one-sided manner. Their use of eye contact is unusual in terms of timing.

According to Wing (1992) over-formal stilted interaction emerges in adolescence or adulthood, in individuals at the more able end of the spectrum who have good linguistic ability. Their interaction is excessively polite and

formal. They seem to have learnt the rules of social interaction, to which they stick rigidly, but without really understanding them. This results in mistakes being made and difficulties with the subtleties of social interaction. As with the other groups there is a lack of understanding of the needs and feelings of other people. This is in the context of some awareness and desire for relationships and social interaction (Jones & Meldal, 2001; Muller et al., 2008). Bauminger and Kasari (2000) concluded from their study of high-functioning autistic children that they are lonely rather than alone, as Kanner had suggested. This implies a desire for social relationships which is impeded in some way.

Impairments of communication

Tager-Flusberg and Anderson (1991) identify a breakdown of the pragmatics of communication as being the universal linguistic feature in autism. Whilst other characteristics of language (phonology, syntax and semantics) may or may not be affected to varying degrees, the core difficulty is in how language is used to communicate socially.

At one extreme individuals may have very limited or no meaningful spoken language and restricted use of gesture, but may grunt, touch or pull to communicate basic needs. Spoken language if present may be restricted to utterances which echo what has just been said, or a replication of something heard in the past, perhaps something heard in a conversation or on television which may be recited word for word, often repetitively, with appropriate intonation, in the absence of comprehension of the content or appropriate context. Those individuals at the other end of the spectrum, who develop speech, have difficulties with their social use of language. This affects various aspects of conversations including turn taking, topic maintenance and flow, and conversational repair following a communication breakdown (Landa, 2000).

Landa (2000) describes the impairment of presupposition which affects the conversational skills of autistic people. In order to plan the content and form of a message to be communicated, the speaker needs to consider the perspective of the communicative partner, being aware of mutually shared knowledge and prior experiences, as well as his/her personal characteristics (for example age, status), contextual variables (for example the presence or absence of a referent), the setting (for example the degree of formality) and previous conversational content. It is also necessary to be able to infer intended meanings from what other people say. Difficulties with this complex set of skills result in instances of inappropriateness during conversational interaction, for

example: failing to recognise when clarification is needed; use of an over formal speaking style; literal interpretation of language especially sarcasm, idioms and jokes; introduction of socially unsuitable topics; and the inclusion of too little or too much detail.

Landa (2000) attributes impaired presuppositional skills in part to impaired comprehension of verbal and nonverbal cues. It may also be a manifestation of poor "theory of mind", one of the cognitive models which may account for the characteristics of autism (see "Cognitive theories of autism"). According to Tantam (2000) abnormalities of nonverbal communication constitute a necessary criterion for Asperger syndrome. All channels of nonverbal expression and interpretation can be affected, including facial expression, posture, interpersonal space, gesture, vocal intonation and gaze behaviour. The result is that individuals appear socially odd and lacking in empathy.

Impairments of imagination

Autistic children do not develop pretend play and other imaginary activities in the same way as other children do. Referring to her London study, Wing (1991) describes the imaginative activities of autistic children as being completely absent, copied meaninglessly from other children, or spontaneous but rigid and repetitive in nature. In adulthood, the impairment manifests as a lack of engagement in activities involving flexible creative thinking, finding pleasure instead in individual special interests. It is also associated with difficulties understanding another person's perspective. Thus there is a lack of social empathy such that autistic people may appear self-centred, eccentric or uncaring. They lack the ability to charm, seduce or disguise, and often fail to perceive this in other people's behaviour (Tantam, 1991) .

Restricted, repetitive and stereotyped activities

Wing (1996) sees this feature of autism as a consequence of the impairment of imagination. When so much is denied to the autistic person in terms of creativity and empathic interest in other people, then reassurance is sought in repeating those activities which do give some pleasure.

Kanner (see Kanner & Eisenburg, 1956) described an obsessive desire for the preservation of sameness, the children in his study becoming distressed by even small changes of routine. This can affect, for example, the order in which daily activities are carried out, the arrangement of one's possessions, attachment to particular objects such as clothing, the range of foods eaten, or

the choice of videos watched. In more high-functioning individuals, repetitive activities are often manifest as unusually narrow and engrossing "special interests" in particular objects or subjects, which lead to obsessive collecting, memorising and reciting of facts. It may become the sole topic of conversation, whilst appearing sterile and excessive to other people, adding to their socially inappropriate persona.

Other features of autism

Additional features commonly seen in autism, but not universal or crucial to diagnosis are: abnormal movements; abnormal sensory perceptual experiences; high levels of anxiety and/or special fears; problems of attention and motivation; and inappropriate behaviour.

Abnormal movements

These may take the form of stereotyped movements, for example finger flicking, flapping arms and hands, rocking, tiptoe walking or facial grimaces, which tend to occur in times of excitement, agitation, anger, or when gazing at something which has absorbed complete attention. The reason for these "stereotypies" is not clear. Wing (1996) suggests that some may be simple repetitive activities, carried out for sensory pleasure, whilst others are a response to overarousal, a normal feature in babies and toddlers, but one which persists in older autistic individuals, who can be distressed if made to suppress their abnormal movements.

Some autistic people appear clumsy, with abnormalities of gait and posture and this can exacerbate the autistic person's pre-existing social difficulties, adding to their apparent oddness and excluding them from group sports and activities.

Abnormal sensory perceptual experiences

Autistic people commonly show deviant responses to various kinds of stimuli, in the absence of any abnormality of basic sensory ability (O'Neill & Jones, 1997). Under and over responsiveness is seen to differing degrees within the autistic population, as well as within the same individual.

Perceptual difficulties include:

- Sensory distortions in the perception of physical objects
- Fluctuating sensory tune-outs or blanking of sound and vision

- Overload of the senses; pain or discomfort due to hypersensitivity, particularly when more than one or two sensory channels involved
- Multi-channel perceptions, for example sensation of colour and smell in response to auditory stimuli
- Difficulty integrating simultaneous stimulation of more than one sensory channel
- Difficulty identifying the channel through which sensory information is being received

Peculiarities of face recognition have been reported (Kracke, 1994), whereby, for example, an autistic person may fail to recognise a known person unless he/she is wearing a particular garment .

Such perceptual abnormalities are disruptive to everyday functioning for autistic people and can account for some odd behaviours, for example the child who frequently removes his clothes because of the distressing sensation they produce on his skin. Sensory over-stimulation reduces the ability of people with ASD to inhibit their responses and manage their behaviours. They may fail to regulate their emotional responses and engage in stereotypical behaviours (Laurent & Rubin, 2004).

Anxiety and special fears

Anxiety arises for autistic people when they encounter situations they cannot understand. Special fears may develop to seemingly harmless things. These may be very long lasting, causing difficulties in daily life.

Problems of attention and motivation

Prior and Ozonoff (1998) summarise the deviant attention to the environment that is characteristic of autism, as oblivious, avoidant and selectively or over focussed. Attention to an object of interest may be sustained for an overly long time, whilst socially relevant stimuli are selectively ignored. There are difficulties shifting attention from one focus to another. Autistic people may also find it difficult to select the relevant aspects of stimuli to attend to and may be easily distracted by irrelevant stimuli. The propensity to over attend is seen as a response to the overpowering effect of stimuli autistic people experience as a consequence of their sensory perceptual difficulties.

An apparent lack of motivation may be secondary to a tendency to focus excessively on special interests to the exclusion of almost anything else (Wing, 1996).

Inappropriate behaviour

The descriptions of autistic behaviour so far include many instances of inappropriateness as a consequence of failure to understand social rules, oversensitivity to sensory stimuli, preoccupation with special interests or repetitive routines, confusion and fear of unfamiliar situations. Behaviour may also be impulsive, difficult to divert or regulate.

In severe cases, the individual may be noisy, restless, destructive, prone to temper tantrums or running away. Those at the more able end of the spectrum will be less extreme in their behaviour, but will lack discretion in their social interactions, making tactlessly truthful remarks or being inappropriately friendly to strangers.

Tony Attwood (2007, p128) describes problems of the intensity and management of emotions characteristic of Asperger syndrome (see also Paxton & Estay, 2007). He quotes Hans Asperger (1991 [1944]):

> *"The children cannot be understood simply in terms of the concept "poverty of emotion" used in a quantitative sense. Rather what characterises these children is a qualitative difference, a disharmony in emotion and expression."*

Deficits of emotional self-awareness, expression and regulation manifest as exaggerated and unusual responses to changes of mood. Anger management problems are particularly challenging for those individuals, and their families, who experience them.

The strengths of autism

Wing (1996) describes the differential pattern of abilities amongst autistic people, with performance on psychological tests of visio-spatial skills tending to exceed performance on linguistic tests. They are visual learners, with strong visual discrimination skills, often able to notice details that others would miss. Three adults studied by Hurlburt and colleagues, reported their thoughts primarily or solely as precise visual images of real-life phenomena, whereas non-autistic adults reported verbal inner experiences, unsymbolised thoughts and feelings as well as visual images (Hurlburt et al., 1994).

Extraordinary visual strengths in some autistic individuals may be manifested as having specific abilities of levels far superior to the normal population; skills such as drawing, playing a musical instrument, mental arithmetic, computer programming. Wing (1996) estimates that one in ten people with autism possess special or "savant" skills such as these. Even those individuals who

would not be described as savant, but who are at least of normal intelligence, are likely to have special interests related to high cognitive abilities (Prior et al., 1998). As well as the potential to excel in specific fields, the characteristic cognitive profile of autism may arguably predispose to qualities such as loyalty, perseverance and integrity.

In favourable circumstances strong cognitive ability and superior visual skills may lead to high academic achievement or a productive career, a famous example being Temple Grandin, a leading figure in the discipline of animal science, as well as an author in the field of autism. However it is clear that people at the high-functioning end of the autistic spectrum have qualities which may be underutilised due to the deleterious effects of other aspects of the condition, and the social marginalisation which pervades their existence.

Jill Aylott (2003) discusses the social model of disability in relation to autism and challenges its fundamental definition as an impairment. She argues that the "primary difficulties for people with a label of "autism" are in relation to understanding a confusing "social" world that is maintained and perpetuated by many social, communication and attitudinal "barriers"." A shift in emphasis to autism as a function of the environment or setting in which the individual operates could draw attention to the way such barriers are perpetuated. (There will be further discussion of the social model of disability in the next chapter, see "CMC and disability".)

The work of Francesca Happe (1999) has directed the interest of autism researchers towards characteristic strengths rather than deficits. She proposed that autistic people could more appropriately be described as cognitively different rather than deficient suggesting that variation along the dimension of central coherence accounted for this difference. This hypothesis was reinforced by Simon Baron-Cohen (2002b) who added another possible explanatory model, the *folk psychology-folk physics* model, a precursor to the extreme male brain theory of autism. (Central coherence and extreme male brain theory will be discussed later, see "Cognitive theories of autism".) He explored the value-laden aspects of the label "autistic" and questioned why the behaviour of higher functioning autistic individuals should be seen as an index of impairment: "Being more object focused than people focused is clearly only a disability in an environment that expects everyone to be social" (Baron-Cohen, 2002b, p491). Similarly Molloy and Vasil (2002) debate whether Asperger syndrome is a disorder or a neurological difference that has been socially constructed as a disorder.

There is a growing consciousness amongst some people of their personal preference for the autistic "condition" (Baron-Cohen, 2002b). They see autism as an integral part of their identity, seeking to celebrate difference and neurological diversity (Sinclair, 1993), rather than pathologising it and striving to cure or rehabilitate against the wishes of the individual (Molloy & Vasil, 2002).

Asperger syndrome and high-functioning autism

It was Lorna Wing (Wing, 1981) who brought the work of Asperger to the attention of clinicians, proposing a broader model of autism to include more able individuals with autistic features. Asperger syndrome (AS) became an official diagnosis in the early 1990's (see DSM-IV and ICD-10, American Psychiatric Association, 1994; World Health Organization, 1993). Classified as one of the spectrum of autistic disorders, the distinguishing feature is an absence of any clinically significant delay in language or cognitive development.

In recent years there has been extensive research and debate as to whether or not AS is the same as high-functioning autism (HFA), a term first used by DeMyer et al (1981), which is yet to gain consensus as to its definition, but which is commonly applied to cases of autism in the presence of normal IQ (Gillberg, 1998). In clinical practice, these terms are often used interchangeably. Indeed Eisenmajer et al (1996) found that many professionals disregard official diagnostic criteria, making the diagnosis of AS, even when there was a history of early language delay or disorder. AS was diagnosed it seemed when individuals showed some social interest and better, although not normal, current verbal skills.

The exclusionary criterion of the absence of language delays is contentious (Gillberg, 1998), in that it often relies on parents' recollections of early language development, since most diagnoses of AS are made at seven years of age or more (Gillberg, 1989).

A comprehensive review by Howlin (2003), of research into possible differences between AS and HFA, found no consistent evidence for major differences in symptomatology or associated problems. Few studies reached conclusive results, due to inadequate matching of groups, small samples and lack of agreement on diagnostic criteria. Her study addressed these shortcomings, and her finding, that the adults with HFA and those with AS both scored below chronological age level on language tests, challenges the view that early language development differs in the two disorders.

Some studies indicate that early childhood differences between the two conditions may diminish with maturity (Gilchrist et al., 2001; Howlin et al., 2000; Mawhood & Howlin, 2000; Mesibov et al., 2001; Tsatsanis, 2003). Gillberg's view (1998) is that a dual diagnosis is possible, and that a diagnosis of HFA and AS can be made in the same individual at different stages of development, implying that the absence of early language delay as a differentiating diagnostic criteria is invalid.

Although Asperger himself did not specify the defining features of his syndrome, other researchers have proposed diagnostic criteria (see Table 1), which Leekham et al (2000) claim bear more similarity to Asperger's descriptions than do the DSM-IV or ICD-10 criteria. On the basis of their study, comparing Gillberg's criteria and the ICD-10 criteria for AS as applied to a group of individuals who met the ICD-10 criteria for autism, they argue that there is considerable overlap between the diagnostic systems, and challenge the value of defining a separate subgroup, suggesting that a dimensional view of the autistic spectrum is more appropriate than a categorical approach.

Reference	Criteria
Ehlers and Gillberg (1993)	1. Social impairments 2. Narrow interests 3. Repetitive routines 4. Speech and language peculiarities 5. Nonverbal communication problems 6. Motor clumsiness
Szatmari et al (1989)	1. Solitariness 2. Impaired social interaction 3. Impaired nonverbal communication 4. Odd speech
Tantam (1988)	1. Language used freely but not adjusted to social context 2. The wish to be sociable but failure to relate to peers 3. Clumsiness 4. Idiosyncratic but engrossing interests 5. Marked impairment of nonverbal communication

Table 1. Proposed diagnostic criteria for Asperger syndrome

As well as the overlap in characteristic features of AS and HFA, there are other factors which may imply a shared aetiology as Frith (2004) describes. Firstly, cases of Asperger syndrome and autism may occur in siblings, implying a common genetic predisposition for the two disorders. There is also some evidence to suggest that there are similarities of brain pathology in both disorders (Bauman & Kemper, 2003). Frith concludes that the prevailing view is that Asperger syndrome is not an essentially different disorder from autism, and located at the higher end of the spectrum of autistic disorders.

Despite the lack of clear differentiation between AS and HFA, Frith (2004) and Wing (1991) disagree with Schopler's view that Asperger syndrome should be abandoned to reduce diagnostic confusion (Schopler, 1985). To parents and individuals receiving a diagnosis, as well as others with no previous experience of ASDs, it may be more acceptable and accessible than the diagnosis of autism, with its more extreme connotations. The introduction of the term Asperger syndrome has highlighted the needs of the more able autistic individual, particularly adolescents and adults, who may have previously remained undiagnosed and deprived of the provision and understanding they need. Klin and Volkmar (2000), however, warn of the risk of people diagnosed with AS sometimes being denied the level of support available to those diagnosed with autism (see also Powell, 2002).

What causes autism?

The precise cause of autism is not known. It is now generally agreed that a number of factors are involved and that autism is a neurodevelopmental disorder with a high heritability, estimated to be 90% according to Rutter (2005; see also Poustka, 1998). The rate of ASD in siblings of individuals with autism is higher than in the general population; 6% compared to 0.5%. A strong genetic component is also indicated by twin studies which have shown a concordance rate of 60% in identical twin pairs in contrast to 5% in fraternal twins. Evidence suggests that there are between 3 to 12, as yet unidentified, susceptibility genes for autism, (Rutter, 2005).

The extreme male brain theory of autism (see "Cognitive theories of autism") proposes exposure to a high level of foetal testosterone as a possible prenatal factor in the aetiology of autism. Research, based on animal experiments, human amniotic fluid sampling, twin studies and data from testosterone-related disorders, suggests that elevated levels of foetal testosterone are positively

correlated with autistic traits and inversely correlated with social development and empathy (see Chapman et al., 2006).

Rodier (2000) suggests that a brain abnormality causing autism occurs very early in gestation, between 20 and 24 days post-conception. Brain imaging techniques have revealed several differences between the brains of autistic and non-autistic people, for example Bauman and Kemper (1994) found evidence of prenatal lesions of the limbic system and the cerebellum in the brains of people with autism. Such abnormalities could interfere with the processing of sensory information, with effects on learning, emotional responses and general behaviour.

Palmen and van Engeland (2004), in their review of neurostructural findings in autism, conclude that after the age of two years individuals with autism tend to have a larger brain volume than neurotypicals, which implies a difference in the neural pruning which normally occurs in childhood. Specifically, the cereballar hemispheres, the parietal lobes and the amygdala are larger, whereas the corpus callosum, which provides a communication pathway between the two hemispheres, is reduced. Results of a brain mapping study comparing five high-functioning autistic adults with five neurotypical controls, suggested a difference in cerebral dominance for the brain areas involved in language listening, from a predominance in the left hemispheres of neurotypical people, to the right hemisphere in autistic individuals (Muller et al., 1999).

Various environmental explanations have been proposed for the rise in incidence of autism over the years, for example the MMR vaccine, but have not been substantiated (Taylor et al., 1999).

Cognitive theories of autism

Before describing the most prominent cognitive theories of autism, I shall outline the characteristics of "autistic thinking" based on the observations of Mesibov and colleagues (Mesibov et al., 2004, see chapter 3), and Paxton and Estay (2007, see chapter 2):

- A predominance of visual thinking
- Excessive focus on detail, with limited ability to prioritise the relevance of details
- Poor self-concept; lack of awareness of their own mental states; limited introspection; relatively poor personal episodic memory (Frith & Happe, 1999; Millward et al., 2000)

- Limited ability to empathise; lack of awareness of the thoughts and feelings of others
- Relatively greater difficulty with symbolic or abstract concepts and language; a tendency to concrete thinking and literal, in preference to contextual, interpretation
- Difficulty combining or integrating ideas; disconnected, individual facts or concepts are easier to understand.
- Inflexibility of thought; difficulty changing conceptualisations; poor problem solving skills; desire for consistency of routine and rules; "grey areas" problematic
- Preference for rule-based, structured, factual information and systems (Baron-Cohen, 2002a)
- Idiosyncratic logic, particularly regarding social understanding, based on associative rather than interactive relationships; prone to faulty assumptions
- Self-organisation difficulties, relating to thoughts, tasks or possessions
- Difficulty generalising skills or knowledge learnt in one situation to a different context.

At the psychological level at least four theories have been proposed to account for autism (for more detailed overviews and relevant research evidence see Russell, 2002; Baron-Cohen, 2002; Frith, 2003). Deficits reflecting all four theories have been found in autistic children, indicating that the theories are not mutually exclusive and that the deficits may share a common underlying neural dysfunction (Gillberg, 1998).

According to Russell (2002) the great surge of interest and research into the cognitive psychology of autism was prompted by the emergence of the deficiency of "theory of mind" hypothesis to account for autism (Baron-Cohen et al., 1985). Subsequent theories are defined in relation to this model, one which, according to Frith (2003), explains the core symptoms of the disorder regardless of the huge variability in their presentation. A deficit of theory of mind impairs the ability to "mentalise", that is attribute mental states (thoughts, beliefs, intentions and feelings) to others, distinct from one's own. Such a deficiency results in difficulties understanding and predicting the behaviour of other people, and a lack of awareness of the impact of one's own actions on other people. According to Frith (2004) individuals at the higher

functioning end of the autistic spectrum may, through effortful learning, develop a logic based theory of mind, one which is restricted by its explicitness, rather than being intuitive in nature. As such it will differ, and be more limited in its impact on social functioning. Based on her analysis of the autobiographical writings of ten high-functioning autistic individuals, Williams (2004) proposed that rather than a theory of mind, neurotypical children have an intuitive ability to mentalise in contrast to the analytical approach autistic people must adopt, which arguably could be seen as "theoretical" in nature.

Frith (2003) accounts for autism by a lack of drive for central coherence, that is a lack of ability to pull information into an overall meaning; to integrate incoming data and draw on context in order to understand. Strong central coherence enables an individual to remember the gist of a story, to understand the common theme or thread in information, to understand broad concepts without necessarily understanding the details. Conversely weak central coherence would result in fragmented, disjointed conceptual understanding and literal interpretation, as well as the strengths of autism, that is, an attention to detail and the potential to develop talents which utilise this skill.

Mottron and Burack (2001) suggest that a fine eye for detail, characteristic of autism, is a consequence of enhanced low level perceptual processing, rather than a lack of central coherence. This hypothesis may account for the unusual perceptual experiences characteristic of autism, for example auditory or olfactory hypersensitivity. Frith (2003) reconciles both hypotheses by highlighting the dynamic nature of information processing, presupposing that bottom-up processing (based on incoming data) is prolific because of the weakness in top-down processing (based on prior knowledge).

Executive dysfunction has also been proposed as the underlying cause of autism, affecting the metafunctions of the mind which monitor, assess, organise and regulate cognitive processes. According to Frith (2003) they enable people to keep several tasks going at once and to switch between them; to make high-level decisions and resolve conflicting sources of information; to counteract or inhibit automatic or inappropriate impulsive behaviour. Deficits affect goal-directed, future orientated cognitive skills: planning, inhibition, flexibility, organisation and self-monitoring (see Prior & Ozonoff, 1998).

Simon Baron-Cohen's extreme male brain theory of autism is a revival of an idea first espoused by Hans Asperger, and is based on a hyper-systemising concept (Baron-Cohen, 2002a). He suggests that there are two dimensions for understanding human sex differences: empathising and systemising. A male

brain is defined in someone who demonstrates systemising abilities far superior to empathising skills, whereas a female brain exhibits the opposite cognitive profile. Systemising is the drive to analyse the variables in a system, to derive the underlying rules which govern its performance. It is an inductive process, involving close examination of variables, analysis of patterns of association and generation of rules. It applies to phenomena which are rule-governed, finite and deterministic; physical rather than psychological. Baron-Cohen argues that using these definitions, autism is a manifestation of an extreme of the normal male profile. In this way he accounts for both the social deficit of autism and the need for sameness, as well as a preference for information about the physical rather than the psychological world.

Frith (2003) explores how the various theories of autism relate to each other and considers whether they reflect separate primary deficits, and as such are all necessary for a full explanation of autism, or whether they may be linked together to provide a unified account. The common theme between central coherence and executive function theories is the lack of balance between weak top-down control and strong bottom-up processing of information. Frith debates the possibility that weak central coherence may be a facet of impaired executive functioning, suggesting that the ability to integrate information from many sources is a metacognitive function. Similarly the ability to attribute mental states may be facilitated by the capacity to process contextual information (Happe, 2001).

Contrary to Baron-Cohen's view (Baron-Cohen, 2002) Frith does not see weak central coherence, which is a piecemeal processing style, as incompatible with systemising, claiming that systemisers typically collect information in self-limiting categories. Baron-Cohen's position is that strong systemisers start their cognitive processing of a phenomenon by focussing on small local details, in an attempt to establish whether they are part of an analysable system. Their social failures relate to problems of empathy, which does not follow predictable rules.

The needs of people at the high-functioning end of the autistic spectrum

Psychosocial outcomes

It would be a mistake to think that people with HFA or AS have only mild disabilities. Being of average or above intelligence they are more likely to be aware of their difficulties and differences, but may be denied recognition and help for their needs because of their intellectual competence and, in some, an

ability to give the appearance of normality in routine interactions, an impression which breaks down in novel or stressful situations (Frith, 2004). This pressure is compounded by a lack of sympathetic understanding by other people who misinterpret idiosyncratic behaviour in someone of normal intelligence and fluent speech with no physical abnormality (Howlin, 1997). This can lead to social isolation, victimisation or exploitation, phenomena for which the individual with AS or HFA lacks the social skills to cope.

The core features of AS and HFA probably become more disabling as an individual approaches adolescence, due to the intense physical, psychological and social changes which characterise this period of life, in the context of, according to Richard Howlin, "an ever-increasing mass media culture [which] is promoting a pseudomaturity in children that emphasises adult image and "fitting in" on ever-changing, superficial terms" (Howlin, R., 2003).

Tantam (1991) points out that AS and HFA are more disabling in adolescence and adulthood when successful social relationships are the key to almost every achievement. Thus despite their intellectual strengths, there are frequent reports of difficulties obtaining and sustaining employment; living independently; developing friendships and long term relationships amongst this group (Barnard et al., 2001; Barnhill, 2007; Cederlund et al., 2008; Engstrom et al., 2003; Howlin, 2000; Howlin, P., 2003; Howlin et al., 2004; Renty & Roeyers, 2006). This is in the context of shortcomings in the definition, organisation and allocation of support services (Barnard et al., 2001; Howlin, 2000; Howlin, P., 2003; Macleod, 1999; Tantam, 2003), a reflection of the tendency to underestimate the extent and impact of the disabilities associated with HFA or AS (Klin & Volkmar, 2000).

Studies which have investigated possible predictors of psychosocial outcomes in adults with AS or HFA indicate that the relationship between IQ and autistic characteristics is a complex one. Szatmari and colleagues (1989) found that outcome in high-functioning adults, based on three scores from the Vineland Adaptive Behaviour Scale (communication, activities of daily living and socialisation) was highly correlated with childhood measures of IQ and nonverbal problem-solving, whilst there was no such relationship with childhood measures of autistic behaviours based on retrospective accounts from parents. However, Howlin et al (2004) concluded that whilst a childhood IQ score of less than 70 predicted poor social functioning in adulthood (based on a composite of ratings of employment, friendships and independent living obtained from parents using the Autism Diagnostic Interview), outcomes in higher functioning

individuals were very variable and the effects of a relatively high IQ could be offset by existing core deficits of autism, particularly the degree of ritualistic and stereotyped behaviours.

Several authors (Howlin, 2002; Lord & Venter, 1992) have suggested that the availability of a supportive social network (family, employment, social services) may also affect outcome in high-functioning individuals. Using self-report measures Renty and Roeyers (2006) investigated autistic trait severity and support characteristics in relation to quality of life (satisfaction; competency and productivity; empowerment and independence; social belonging and community integration) in 58 high-functioning adults. In contrast to the suggestions of Howlin et al (2004), there was no evidence for a significant association between autism-specific traits and quality of life. However quality of life was positively associated with the level of perceived informal support, and negatively correlated with the number of unmet formal support needs. A higher quality of life was also associated with smaller discrepancies between received and needed formal support in the areas of accommodation, daytime activities, ASD-specific information, company and intimate relationships. The authors relate their findings to the social model of disability, whereby disability is less a product of the factors within the individual and more of the interaction with the environment. They emphasise the importance of a good "person-environment fit."

Forensic problems

In some instances the emotional difficulties associated with AS or HFA as well as difficulties with social empathy, can result in frustration and anti-social behaviour (Tantam, 1991). Social naivety and a desire for friendships may create vulnerability to being led into delinquent behaviour. However, although a link between criminal behaviour and autism spectrum disorders has been suggested, Ghaziuddin (2005) concludes that the validity of this claim is questionable since it is derived from single case reports or studies of specialised forensic samples such as maximum security hospitals (see also Allen et al., 2008; Howlin, 2002). Several authorities (for example, Frith, 1991) have argued that the majority of people with AS or HFA are actually scrupulous in their adherence to the law, relating this to literal and rigid thinking. There is a need for large scale community-based studies to investigate whether it is the case that people with ASDs are particularly prone to violent or offending behaviour.

Analyses of case histories (Barry-Walsh & Mullen, 2004) and interviews with adults with Asperger syndrome who have engaged in offending behaviours (Allen et al., 2008) have yielded various autism-related factors which may predispose an individual to offend: lack of concern or awareness regarding the implications of their behaviour, obsessional pursuit of a desired outcome or special interest, social naivety, misinterpretation of rules, difficulty expressing emotions or interpreting those of others, tendency to misread other people's behaviour, poor impulse control, vulnerability to exploitation by others and poor social skills. Precipitating factors included: permanent school exclusion, bullying, job losses, family stress, relationship problems, and long histories of mental health problems and substance misuse (Allen et al., 2008).

Psychiatric comorbidity

Due to constant pressure to fit in socially and cope with sensory abnormalities, communication difficulties, confusing social situations, changes of routine and the social problems outlined above, people with AS or HFA are prone to low self-esteem, stress and anxiety which Attwood (2003) suggests makes them vulnerable to mood disorders (see Ghaziuddin, 2005). Such disorders may be masked by the autistic disorder and may go unnoticed or be misdiagnosed. Although no large scale population studies have been performed, reports from evaluation clinics suggest that panic and anxiety disorders are common (Ghaziuddin et al., 1998; Green et al., 2000) as is depression (Ghaziuddin et al., 2002; Ghaziuddin et al., 1998; Green et al., 2000; Stewart et al., 2006; Tantam, 1988) bringing risks of suicide and substance misuse. Other psychological problems which may occur in people with ASDs include phobias, paranoid or delusional thinking (Clarke et al., 1989; Craig & Hatton, 2004; Kurita, 1999), catatonia (Wing & Shah, 2000), and compulsive disorders, including obsessive-compulsive disorder (Ghaziuddin, 2005; Raja & Azzoni, 2001).

There is a suggestion that psychological disorders may be more prevalent amongst individuals at the higher functioning end of the autistic spectrum than their lower functioning counterparts. However it may be that higher functioning autistic people are more able to report their symptoms enhancing the likelihood of diagnosis (Ghaziuddin, 2005).

The basis of psychiatric comorbidity

In addition to the secondary emotional factors associated with the disability of AS or HFA, there may also be constitutional factors which contribute to the higher incidence of psychological disorders amongst this population. A higher than expected incidence of depression, which cannot be entirely accounted for by the stress of raising a child with a disability, has been found in the family histories of children with Asperger syndrome or autism, which suggests there may be a genetic predisposition amongst this population (Bolton et al., 1998; Ghaziuddin & Greden, 1998; Piven & Palmer, 1999). Other psychiatric disorders which have been found to be more prevalent in the families of autistic children include social phobia (Piven & Palmer, 1999), motor tics, obsessive compulsive disorder (Bolton et al., 1998) and bipolar disorder (De Long, 1994).

Current theoretical models of autism may also explain why individuals with AS or HFA are prone to affective and other psychological disorders (Anderson & Morris, 2006; Attwood, 2003; Paxton & Estay, 2007).

Impairment of various aspects of executive functioning, purported to underlie the core characteristics of autism, may contribute to distorted or dysfunctional thoughts and concepts and false assumptions about one's circumstances and the intentions of other people, resulting in a disposition to emotional disorders; for example a lack of central coherence underlying literal interpretation and concrete, narrow or fragmented thinking. Cognitive inflexibility would make any distortions of thought resistant to change, as well as impeding problem solving thereby limiting emotional coping, and contributing to perseverative thoughts which may generate anxiety. An impairment of self-restraint and self-control may account for a tendency to react to emotional cues without cognitive reflection or regulation. Neuro-imaging studies of subjects with autism have identified functional and structural abnormalities of the amygdala, an area known to be involved in emotional control (Abell et al., 1999; Baron-Cohen et al., 2000). Impaired inhibitory functions may also contribute to impulsive or compulsive behaviour.

According to the theory of mind model, people with ASDs have difficulty identifying and conceptualising the thoughts and feelings of other people as well as their own and this can result in social misunderstandings, distorted thinking and difficulties coping with one's own emotions as well as those of others. This may result in a poor or distorted sense of self in people with Asperger syndrome as described by some authors (Attwood, 2003; Howlin, R., 2003), and supported by some experimental evidence (see Millward et al., 2000; Toichi

et al., 2002). For some this may be experienced as severe self-doubt and self-criticism which could precipitate anxiety and/or depression, whilst in others it may be manifested as arrogance and omnipotence which could be associated with anger management problems (Attwood, 2003).

Another possible consequence of impaired theory of mind is the development of paranoid or delusional thinking due to incorrect inferences of the intentions of others based on their behaviour (Anderson & Morris, 2006; Attwood, 2003). However, based on their research, Abell and Hare (2005) propose a more complex relationship between theory of mind ability and delusional belief in Asperger syndrome whereby the combined effects of cognitive impairments (theory of mind, executive function and autobiographical memory) seriously disrupt normal social functioning and may lead people to develop negative thoughts about themselves, other people and the world around them, resulting in lower self-esteem and increased self-consciousness. Grandiose delusions may develop as a means of protecting a vulnerable self-esteem. The discrepancy between the delusional beliefs and real life experience may serve to produce more negative thoughts and emotional distress thereby sustaining the need for delusional thinking. The authors propose that paranoid thinking is a result of heightened self-consciousness associated with an attentional bias toward information which reinforces negative thoughts. Paranoid thoughts may be maintained by consequent avoidance behaviour reducing opportunities for false beliefs to be disconfirmed

The cognitive difficulties which may contribute to a propensity to emotional dysregulation and disorder, may be compounded by the sensory abnormalities and fluctuations which characterise ASDs and also the loss of emotional control which occurs in states of overstimulation or anxiety (Laurent & Rubin, 2004).

Interventions for autistic spectrum disorders

Over the last 50 years many treatments of various kinds (dietary, pharmacological, psychological, educational) have emerged as therapeutic approaches for autistic spectrum disorders, particularly in childhood. Despite claims of significant improvements in outcome, or even cure, made for some of these interventions, there is a lack of rigorous research to substantiate such assertions. As Tantam (2005) points out, it is widely accepted that autism is a neurodevelopmental disorder and therefore the primary cause is incurable. However interventions such as the TEACHH programme aim for improved adaptation, rather than normalcy (Mesibov, 1992). This may be achieved by

enhancing individual skills and, equally important, altering the environment to accommodate deficits.

Howlin (2002) warns against the view that one approach is successful for all and emphasises the need for individually designed programmes which take into account the underlying autistic deficits and the individual's personal strengths, needs and circumstances. Therefore interventions may draw on a number of different techniques. The most effective interventions are those which (see Howlin, 2002; Mesibov 1992):

- are founded on structured teaching and environmental organisation
- accommodate the communication deficits of the individual for example through the use of clear simple language and use of visually based cues
- focus on skill enhancement and establishment of more effective communication strategies to reduce challenging behaviour and enhance social functioning
- provide opportunities for real-life social interaction in which to practice skills and experience satisfying social contact
- establish explicit rules or guidelines for appropriate social behaviour
- accommodate individual needs for rituals, routines or special interests, by establishing clear boundaries

Howlin (2002) stresses the importance of early diagnosis and provision of advice and support for parents and other key people in order to minimise or avoid problems later. Therefore home-based interventions, as well as specialist early years educational programmes, have been designed specifically for young children (Magiata et al., 2007; McConachie & Diggle, 2007) in addition to school-based interventions (for example TEACHH, see Mesibov et al, 2004). Unfortunately early diagnosis is relatively rare in higher functioning autistic children whose disabilities are more subtle in their presentation. A survey of 156 British parents of children with Asperger syndrome obtained an average age of diagnosis of 11 years, despite parental concerns emerging typically at 30 months (Howlin & Asgharian, 1999). Compared to parents of children with lower functioning autism, parents of AS children experienced more frustration and greater delays in the pursuit of a diagnosis. They were more likely to be told there was no foundation to their worries, or reassured that their child would "grow out of it."

As higher functioning individuals reach the challenges of adolescence and adulthood the overall goal of therapeutic support is to improve self-management skills (Howlin, R., 2003). A key area is the development of social understanding and interpersonal behaviours, providing strategies to cope with problems faced at school, work or other social situations. Several authors (for example Howlin & Yates, 1999; Mesibov, 1992) have documented the potential to address this aim by means of social skills groups, in which issues are discussed and skills taught in structured learning activities (for example use of video and role-play) and then practiced in natural social situations.

The role of psychotherapy

Individual counselling or psychotherapy may help people with AS or HFA cope more effectively with their emotional or practical difficulties. Several authors have written of the suitability of cognitive behavioural therapy (CBT) for high-functioning autistic individuals (see Anderson & Morris, 2006; Attwood, 2003; Paxton & Estay, 2007; Ramsay et al., 2005). CBT is problem-orientated and focuses on the behavioural, emotional, cognitive and environmental aspects of an individual's distress. It is more structured and less abstract in its conceptual demands than other forms of psychotherapy. The approach focuses on how people conceptualise their emotions, and aims to change dysfunctional or illogical thinking and false assumptions. Therefore it has direct applicability to people with AS or HFA since, according to psychological theories of autism, distorted thinking and deficient emotional awareness and management are core aspects of the condition. Additionally Ramsay and colleagues (2005, p488) attribute the suitability of CBT to its tendency to target the "automatic in the moment reactions of AS patients."

CBT has been adapted for people with AS or HFA to enhance their social, empathy and problem solving skills, as well as to help them manage their emotions and deal with low self-esteem, stress and comorbid psychological difficulties such as anxiety or depression. Anderson and Morris (2006) identify particular aspects of CBT, and appropriate modifications, which may inform good practice in psychological work with high-functioning autistic people:

- Greatly increased use of written and visual material in view of the predominantly visual mode of thinking
- Greater emphasis on affective education: the recognition of signs of emotion and emotional crisis in oneself and others; the relationship

between cognition, affect and behaviour and physical symptoms; the impact of one's actions on the emotions of others

- Avoidance of the use of metaphor or abstract concepts in view of the literal, rigid thinking style
- A more directive approach than is usual in CBT (or other forms of psychotherapy), judiciously used when appropriate
- Involvement of a family member or key-worker as co-therapist in an attempt to improve generalisation of skills

Attwood (2003) also sees an effective stress management programme as an essential component of CBT for people with AS or HFA. This should include problem-solving interventions, traditional relaxation techniques and environmental modifications.

In view of generalisation difficulties characteristic of HFA or AS, Ramsay et al (2005) highlight the importance of the experiential component of CBT, through role-play and specific behavioural experiments or assignments in real-life situations.

Although CBT apparently has much to offer the individual with AS or HFA, the psychotherapeutic process is challenged by aspects of the autistic disorder (see Ramsay et al, 2005):

- There may be problems of motivation due to lack of self-awareness such that most people with AS or HFA who pursue psychotherapy only do so at the suggestion of someone else.
- Poor nonverbal communication and literal interpretation can create misunderstandings and sabotage the therapeutic relationship and rapport.
- Deficits of theory of mind and cognitive inflexibility may serve to create unrealistic expectations of others which are hard to relinquish.
- Due to a history of negative social experiences, clients may understandably be sensitive to comments which could be perceived as criticism, particularly from someone new and unfamiliar.

Therefore the authors emphasise the need for sensitivity on the part of the therapist, who should take time to get to know the client and learn about their interests, inner experiences and style of communication. They should be aware of the potential for misunderstandings and query clients about their thoughts

and reactions to the therapists' statements and behaviours. Similarly therapists should also be conscious of their own potentially negative reactions to the client and its impact on the therapeutic relationship.

Empirical investigations into the effectiveness of CBT with high-functioning autistic people have yielded positive outcomes although evidence is limited to a small number of case studies of CBT where symptoms of comorbid psychological problems (depression, self-injurious behaviour, anxiety, anger management problems, obsessive-compulsive disorder) had decreased (see Cardaciotto & Herbert, 2004; Hare, 1997; Kellner & Tutin, 1995; Reaven, 2003), and two group intervention studies. Soronoff and colleagues (2005) conducted a randomised control trial of group CBT for anxiety in children with AS. Outcomes of six weekly two hour sessions of therapy were measured in an intervention for child only group (n=23) and an intervention for child and parent group (n=25), and compared to a waiting list control group (n=23). The two intervention groups demonstrated significant decreases in parent-reported anxiety symptoms at six weeks post treatment, more so in the parent and child group. In a study conducted by Bauminger (2002), high-functioning autistic children received an individual programme of cognitive behaviour therapy which focussed on interpersonal problem-solving, affective knowledge and social interaction taught by their main teacher at school, in conjunction with a typically developing peer and the child's parents. There were significant improvements in positive social interaction, emotional understanding and social problem-solving

A holistic approach for a pervasive condition

Given their finding that quality of life for people with AS or HFA was associated with the number of unmet support needs, Renty and Roeyers (2006) recommend that a full assessment of met and unmet needs, from the viewpoint of the individual, should be the foundation for planning and evaluating intervention. Thus management may include support to obtain accommodation and social contact, as well as the involvement of other services such as careers guidance, supported employment schemes, and relationship and sexuality education (see Attwood 2003).

This discussion of interventions for people with autistic spectrum disorders has raised many aspects to be considered in meeting the needs of this group. The core approach is to aim for adaptation not normality, by enhancing individual skills and modifying the environment. As an additional and final thought,

however, I would like to reinforce the pragmatism of Digby Tantam, (2005) who highlights the social marginalisation of people with HFA or AS, and the negative impact of bullying, pity and over-indulgence. Whilst counselling and support groups can help, there is a need for a change of culture in which people with HFA or AS are treated with respect, and have the opportunity to experience themselves as agents with the power to make a difference to their own fate. In his book "Doing Internet research" Steve Jones (1999, p2) claims that "The Internet is not only a technology, but an engine of social change." In the next chapter I will explore this claim and the opportunities the Internet may offer for people with HFA or AS to counteract the social isolation and exclusion they face in their lives.

CHAPTER 3: THE INTERNET AND COMPUTER-MEDIATED COMMUNICATION

An introduction to the Internet

I shall begin this chapter with an overview of the Internet, outlining the history and ongoing development of this technology, identifying its main sub-systems and communication genres as well as describing the growth, distribution and activities of the online population in contrast to those on the other side of the "digital divide".

The evolution and growth of the Internet

It is probably not an overstatement to say that the advances in computerisation and digital technology from which the Internet has evolved, constitute a revolution in the field of communication, one which is now embedded in the everyday lives of people in the developed world. According to Slabbert (2007), the Internet is rapidly becoming a basic feature of global civilisation, with the result that what has traditionally been called civil society is virtually synonymous with an information technology society as defined by Internet use.

In simple terms the Internet, as it exists today, is an almost global, publicly accessible series of interconnected computer networks which enables the transfer of data between computers. This "network of networks" comprises millions of smaller domestic, business, academic and government networks which together make the Internet "a world-wide broadcasting capability, a mechanism for information dissemination, and a medium for collaboration and interaction between individuals and their computers without regard for geographic location" (Leiner et al., 2003). The development of the Internet can be seen as the continuation of the drive which brought us the invention of the telegraph, telephone and radio, that is the desire to communicate increasingly large amounts of information over greater and greater distances, at ever increasing speeds, and to a wider and larger population (Thurlow et al., 2004).

The origins of the Internet can be traced back to the 1960s (Kristula, 2001; Leiner et al., 2003) when the US Air Force commissioned Paul Baran to explore how information could be exchanged between locations on a decentralised

military network in the event of nuclear attack such that command and control over armaments could be maintained. His final recommendation was the use of packet switching:

> *"Packet switching is the breaking down of data into datagrams or packets that are labeled to indicate the origin and the destination of the information and the forwarding of these packets from one computer to another computer until the information arrives at its final destination computer. This was crucial to the realization of a computer network. If packets are lost at any given point, the message can be resent by the originator."*

In 1969, on the basis of this recommendation, the United States Defense Department developed a network, consisting initially of four nodes, called the ARPANET. The first email programme was written in 1972. In 1973, the U.S. Defense Advanced Research Projects Agency (DARPA) initiated a research program to investigate techniques and technologies for interlinking packet networks of various kinds. The system of networks which emerged became known as the Internet.

The first international packet switched network service, referred to as the International Packet Streaming Service (IPSS), was developed in 1978 by a collaboration between the British Post Office, Western Union International, and the United States' Tymnet. This network was to grow from Europe and the USA to cover Canada, Hong Kong and Australia by 1981, and by the 1990s to provide a worldwide networking infrastructure.

In its early stages, the network was used largely by academics for information exchange and also for the remote access of powerful computers, thereby expanding collaborative opportunities. The late 1980s saw the introduction of commercialisation and the beginning of a period of expansion of the Internet, which included the creation and growth of email services and Internet Service Providers, and the formation of interconnections between more and more of the various commercial, government and academic networks which were now emerging.

In 1990 Tim Berners-Lee at CERN implemented a hypertext system to provide efficient information access to the members of the international high-energy physics academic community. This led to the development of the World Wide Web, a system of interlinked documents, or web pages, accessed via the Internet. Software applications called web browsers enable users to view and

navigate between web pages which over the years have developed in their content to include not only text, but also images, sounds, videos and interactive content.

By the late 1990s, with the growth of the World Wide Web and increasingly widespread use of personal computers, including public and home access, the Internet was attracting a large amount of public and commercial interest, and was estimated to be doubling in size yearly (Coffman & Odlyzko, 1998). As increasingly high speed connections become available and technology becomes more affordable and mobile, the number of users worldwide continues to grow rapidly. In 2007, there were estimated to be 1.244 billion Internet users, comprising 18.9% of the world population, a growth of 244.7% from the previous year (Internet World Stats, 2007).

The World Wide Web has grown into a diverse information resource which can be easily and instantly explored by users anywhere in the world through the use of key word driven search engines. There is no central administration or regulation of the web and hence any individual or organisation, be they commercial, personal, political or public in nature, may publish their ideas or information online and potentially reach a very large population. As a result the web has expanded to contain, at the time of writing, at least 24.48 billion pages (de Kunder, 2007).

As well as a huge source of information, the World Wide Web has also evolved into a common interface for the access of other Internet-based facilities, that is digital data transfer, remote access to other computers and information stores anywhere in the world, and a range of interpersonal communication channels which has expanded to include real time text chat, audio video conferencing, voice telephony, as well as email.

Internet-based services continue to evolve and emerge in conjunction with technical innovation and social trends (Thurlow et al, 2004). Online shopping, banking, games, education, training and participation in forums such as chat rooms and bulletin boards are examples of amenities now on offer via the Internet. The capacity to transfer any data which can exist in digital form via the Internet is transforming the sale and distribution of many products such as print publications, software products, news, music, film, video, photography, graphics and other arts. It has also enabled the sharing of such commodities as people outside the commercial sphere upload their own images, videos or audio recordings onto sites such as You Tube and Flickr.

At the level of the individual, blogs, which are chronologically organised "web logs" frequently serving as ongoing online journals, are becoming increasingly popular as are personal web pages and their incorporation into social network sites such as MySpace and Facebook, through which people may develop new contacts with other people online. Online digital broadcasting is another rapidly growing Internet trend, a medium used not only by radio and television companies, but also individuals using personal webcams.

Despite its relative newness, the Internet for many people in the richer countries of the world has become a pervasive part of daily living, perhaps one which is now taken for granted and, some may speculate, is a necessity on which society is dependent (Thurlow et al, 2004). Indeed there are those who argue that we have entered a new era of human society, in which information and knowledge has replaced capital and labour as drivers of economic growth (see Michailakis, 2001). The overlap between online and offline life is becoming greater and greater for many users. The services available online have implications for our everyday lives affecting the what, where, who, when and how of our working practices, domestic and leisure activities, as well as communication and interaction with other people and organisations.

Computer- mediated communication

The focus of this research will be on the human communication and social interaction which can take place via the Internet as opposed to media or mass communication. The perspective taken is of communication as a dynamic, transactional process, which is multifunctional and multimodal (Thurlow et al, 2004) rather than a more static linear information-processing model.

Various ways of communicating online have emerged as the Internet continues to grow organically. The first communication tool to be developed was email by which electronic text messages, analogous to letters, notes or memos, can be sent via the Internet from one computer to another in as little as a few seconds or minutes.

By means of electronic mailing lists a message sent to a single address can be distributed to all the members of a particular group. Such groups may be based around a common interest or shared purpose, which could be related to participants' work, domestic, leisure or personal lives. Mailing list memberships may originate from established offline organisations or they may have been formed through online networking and communication. Some mailing lists serve as announcement lists by which a limited number of people send information

one-way to the group membership, whilst others invite discussion, any subscriber being able to post to the list which may prompt a response thereby encouraging conversation or debate to develop. Some groups may have rules for acceptable online behaviour, and a moderator who intercepts all messages before forwarding, filtering out those considered to be inappropriate, irrelevant or offensive. Other groups function without such intervention.

Online discussions may also be hosted by websites to which participants can post their messages which will be displayed in chronological order, or organised into thematic groups or "message threads" for others to log on and view. These forums may be referred to as bulletin boards or message boards, and they are functionally similar to newsgroups, which preceded the web forums and which operate via Usenet, a separate global, decentralised, distributed Internet discussion system. Online discussion forums are similar to blogs, but usually have more questions and answers, whereas blogs in the main contain general commentary from the author, although feedback or comment may be invited.

The Internet-based communication genres discussed so far have in common their lack of synchronicity. Participants do not interact in real time and do not need to be online at the same time. More recently synchronised forms of communication have become available via the Internet. Text messages may be exchanged between two or more people online at the same time via instant messaging websites or chat rooms. Instant messaging usually occurs between two people, who may invite a third party to join in, whereas chat rooms are set up for group discussions, one person's contributions being visible to everyone else online at the same time. Similar to asynchronous electronic discussion groups, chat rooms are often organised around a specific topic. Text chat enables fast online interaction and has given rise to mechanisms to cut down on typing and to convey inflection and emotion, by the use of devices such as abbreviations, acronyms and emoticons, as well as a lack of emphasis on grammar and punctuation. This elliptical style of language is becoming more evident in other forms of textual communication in particular mobile phone text messaging, but also email and, more worryingly, my teenage daughter's English homework!

Another type of forum for synchronous communication is the multiuser virtual environment often associated with online role playing games, but also used for distance learning, conferencing or social networking. Originally these were text-based environments containing descriptions of rooms, landscapes, objects, events and other characters to create an atmosphere in which players

communicate and interact via text chat. However 3D graphical environments are now emerging such as the social avatar world Second Life, which is created by its users who may interact with each other via text or voice chat in a way which is more akin to face-to-face encounters than other forms of CMC. By means of their personally designed movable avatars, residents of Second Life can socialise, take part in group or individual activities, and use virtual money (which is exchangeable for real world currencies) to create and trade items and services with each other. As Second Life has evolved so have instances of it melding with the real world for example: several universities have virtual classrooms there; a diverse range of real-life products have been promoted there by companies such as Adidas, Dell, Mazda and Coca-Cola; other companies have used it to prototype their products; charitable and political organisations can promote real-life causes; and some nations, for example Sweden, have opened embassies there by which they may promote their country to a global audience, or provide information on aspects of policy such as visas and trade.

With the continuing evolution of online services, there has been a drive toward multi-media online communication and for more communication which is not text-based. Hence there is increasing use of telephone and video conferencing via the Internet as well as the use of webcams in conjunction with instant messaging services. However, at the time at which this research commenced, audiovisual forms of communication were not widely available. Therefore text-based Internet communication, which at the time of writing continues to be the most widely used type of online communication, was the main focus for this study. The research findings will, however, be considered in the context of the ongoing growth and development of the Internet and computer-mediated communication.

It is clear from this overview that the Internet can provide a diverse and extensive range of facilities to those who use it. However it is not universally available as I shall now discuss.

The Internet population and the digital divide

Internet penetration and patterns of use

Although the global Internet population is currently doubling in size each year, there are large disparities between its penetration in different regions. North America, Australia/Oceania and Europe have the largest proportions of citizens online (as of 2007, 70%, 55% and 42% respectively), whilst the less developed

continents have much lower penetration rates, for example 5% in Africa and 12% in Asia (Internet World Stats, 2007). With a growth between 2000 and 2007 of one third to over two thirds of the population online (Dutton & Helsper, 2007), the UK, along with the Nordic and Benelux countries, has one of the higher rates of penetration in the European Union (Ottens, 2006; Internet World Stats, 2007), whereas Internet use is less evident in eastern and southeastern countries for example Bulgaria (29%) and Poland (30%).

There has been a rapid growth in the domestic use of high speed connections to the Internet. In 2007 56% of UK households now have broadband (constituting 85% of all households with Internet access), compared to 36% in 2005 (Dutton & Helsper, 2007; National Statistics, 2007). The use of mobile handheld access has also increased, from 10% of users in 2005 to 21% in 2007.

In general, people are accessing the Internet more frequently and spending more time online. In the UK in 2007 67% of users were going online daily, constituting an increase of 14% from the previous year (National Statistics, 2007). In the month of June 2007 the average Briton spent a total of 17 hours and 21 minutes online (Nielsen//NetRatings, 2007a). Younger people are the most active group, 70% of 16-44 year olds going online every day compared to 46% of over 65 year olds (National Statistics, 2007). According to a survey in the United States, access to broadband, rather than previous years of experience, is now a more significant predictor of online behaviour, in terms of the frequency of Internet use and the range of activities undertaken (Fox, 2005).

The most recent surveys of Internet use in the UK (Dutton & Helsper, 2007; National Statistics, 2007) indicate that the Internet is used most for sending or receiving email and searching for information about goods and services with around 90% of users reporting they use the Internet for those purposes. In terms of communication, instant messaging is also popular, 61% of users going online for this purpose (Dutton & Helsper, 2007). One of the most recent phenomena to emerge on the Internet is the social network site. In a two year period 2004-2006, the number of such sites on the World Wide Web almost doubled from 125 to 223, and there was a fourfold increase in the number of members from 115 to 490 million (Golbeck, 2007). Regarding the creation of social contacts online, the Oxford Internet Survey (Dutton & Helsper, 2007) found that 23% of Internet users had made new social contacts online. Of these 47% had gone on to meet them in person.

The results of the Oxford Internet Survey (Dutton & Helsper, 2007) indicate differences in patterns of use associated with gender or lifestage. Overall men use the Internet more than women for most activities particularly entertainment and those involving content production, for example posting photographs or maintaining a website or blog. Women are more likely than men to go online to search for health information. These gender differences however are not large. According to Banerjee et al (2005), the pattern of differences in Internet uses between men and women in the US differs from that of the UK. Their survey indicated that women use the Internet more than men for email, instant messaging, online courses, job hunting, and searching for information about health issues, government matters or commercial products and services. Conversely, men are more likely to go online to play games, use online forums, download films, television or radio broadcasts, make telephone calls, get the news, weather or sport, or access online banking or financial trading.

In terms of lifestage (see Dutton & Helsper, 2007), students are the most active users of the Internet for social, communication and entertainment purposes, whilst employed people are frequent users of financial services and information seeking sites. Retired people are the least active Internet users in all areas, apart from civic participation and financial sites. Although social networking remains a small but growing phenomenon, with only 17% of users maintaining an online profile, it is particularly popular with young people and students. 42% of this group of online users are involved in social networking sites, compared to 15% of employed people and 2% of retired people. They are also the group most likely to make friends online, although they are least likely to then meet them offline. Retired people (60%) are more likely to pursue online contacts in the offline context than employed people (47%) or students (38%).

The digital divide

Although there is a rapid growth in the size and activity of the Internet population, there are great discrepancies in the penetration of information and communication technology between particular groups, a phenomenon known as "the digital divide." I shall now describe these inconsistencies, explore the factors associated with digital exclusion and the implications of this divide.

As already discussed there is a global digital divide, with developing countries lagging far behind in their adoption of ICT, for example 70.4% of the US

population are Internet users, whilst the proportion in India is 5.3% and in Ethiopia 0.2% (Internet World Stats, 2007).

Within the UK, although the number of non-users is falling, a quarter of the population in 2007 had never used the Internet and digital divides continue to exist (Dutton and Helsper, 2007; National Statistics, 2007). Women, retired, disabled, lower educated and lower income people are all less likely to use the Internet than men, students, higher educated and higher income individuals. Similar divides exist in the US, although there is no longer a gender gap (Pew Internet and American Life Project, 2007). Indeed in the UK the difference in use between men and women (70% as opposed to 65%) is the smallest of the digital divides (Dutton & Helsper, 2007), and there is evidence that it is narrowing in certain age groups; 18-34 year old women are now the most prevalent demographic group online in the UK (Nielsen//NetRatings, 2007b).

Dutton and Helsper (2007) conclude that age and life stage are strong correlates with Internet use. Students are three times more likely to use the Internet (97%) than retired people (31%). Between 2005 and 2007 there was a proportionally higher increase in Internet use in 18-54 year olds compared to the over 55 age group.

Although the use of the Internet is increasing in all income and ability groups, there is still a large disparity between different levels. Only half of people educated up to secondary school level are online, as opposed to 90% of university educated individuals. People with the highest incomes (over £50,000 per annum) are more than twice as likely to use the Internet as those on the lowest income levels (below £12,500).

Despite having a greater perceived impact on quality of life for disabled people online compared to their non-disabled counterparts, the Internet is less available to people with disabilities (Dobransky & Hargittai, 2006; National Organization on Disability, 2002; Pilling et al., 2004). In the UK in 2007 (see Dutton & Helsper, 2007) the proportion of disabled people who used the Internet (36%) was half the proportion of people without disabilities (77%).

There is also evidence of a rural/urban divide. A survey in the US in 2007 found that 73% of the urban or suburban population were Internet users, compared to 60% of rural residents (Pew Internet & American Life Project, 2007). Within the EU Internet use is more prevalent in densely populated regions (62%) compared to predominately agricultural regions (24%) (Commission of the European Communities, 2005; Milicevic & Gareis, 2003).

In recent years a new dimension has emerged in the phenomenon of digital exclusion: differences in Internet access speed (Warren, 2007). High-speed broadband connection to the Internet confers benefits such as faster file transfer, real-time video links, interactive gaming, as well as being available without precluding telephone use. Most websites are now designed in accordance with broadband provision, disadvantaging those with modem access. An American study (Fox, 2005) found that there are two tiers of Internet users in addition to the 27% of the population who are non-users, or who do not have Internet access. The availability of broadband was an important factor differentiating between those who are "loosely" connected to the Internet and those who are "highly wired". The 40% with loose connections are less fervent in their Internet use and typically use dial up connections, whereas the 33% highly wired group go online at home via high-speed connections, more frequently and engaging in a wider range of online activities. Differences in quality of Internet access are partly determined by geography, broadband being far less available in rural areas, as well as socioeconomic factors such as income and education (Warren, 2007).

Digital exclusion is a complex and dynamic phenomenon. In some cases, for example the gender divide, the gap is narrowing as more of the affected group adopt the technology, albeit more slowly, eventually catching up with the rest of society. In other instances adoption of the technology is limited by a factor characteristic of that particular group (for example disability, income, location, education), hence the divide widens over time and ultimately there is a shortfall in maximum penetration (see Warren 2007). Defining digital inclusion as having home Internet access, the Future Foundation (2004) predicts that if there is no progress towards producing more standardised, affordable, user-friendly information technology, more than a third of the UK adult population will remain digitally excluded in 2025.

Barriers to digital inclusion

From their detailed analysis of digitally excluded people in Britain, the Future Foundation concluded that there are two broad types of inhibitors to digital inclusion (Future Foundation, 2004). Firstly there are problems of access, which are often associated with income and the capacity to pay for technology. Other issues also have implications for access, for example disability (physical, sensory, or learning), skills gaps and geographical location. Reasons for not using the Internet given by participants in an EU study indicated that income and education were major determinants in digital exclusion (Commission of the

European Communities, 2005). Non-use was reportedly due to: non-availability of a PC at home combined with lack of access at work or a public access point; the high cost of PC ownership and Internet connection; the complexity of the technology and lack of basic skills.

A cross country analysis of Internet penetration by Chinn and Fairlie (2006) concluded that the global digital divide was largely due to income differentials although the quality of telecommunications infrastructure and regulatory infrastructure were also important factors. Policy was also identified as a factor in its own right in a guide for community-based adoption and use of ICT produced by the Center for International Development at Harvard University (Information and Technologies Group, 2000).

The second type of problem affecting digital inclusion is that of engagement whereby people do not perceive the need or benefit of the technology. This may relate in part to another obstacle identified by Sevron (2002): the relevance and utility of content to different sections of society. Van Dijk also highlights barriers of mental access which relate to confidence, motivation and attractiveness of the human-technology interface (see van Dijk & Hacker, 2003). These sorts of barrier were also raised by respondents in the EU study; 30% had no desire or interest in going online. Reasons for non-use included lack of awareness, lack of time, language barriers and unavailability of useful content (Commission of the European Communities, 2005).

The Oxford Internet Survey (Dutton & Helsper 2007) revealed differences between ex-users and non-users in reasons given for exclusion. Whilst both groups identified high cost and lack of access as relevant, ex-users most frequently attributed their non-use to lack of interest or perceived usefulness, whereas non-users were more likely to cite lack of skill. The authors suggest therefore that the exclusion is largely a matter of choice for ex-users whilst for non-users it is a matter of fear or lack of skills, and hence not a positive choice.

There were also differences between demographic groups in their reasons for not using the Internet. The Oxford Internet Survey found that women, unemployed and retired people were less likely to report disinterest in the Internet and frequently attributed their exclusion to lack of access or skills. Retired people tended to feel that the Internet did not meet their needs, whilst unemployed people were the group most likely to cite cost as a barrier to going online. Dutton and Helsper conclude that digital divides are "driven by socio economic resources and a set of "digital choices" shaped by cultural differences." (Dutton & Helsper, 2007, p11)

The link between social exclusion and digital exclusion

Having discussed the increasing range of facilities and services available via the Internet it is clear that compared to Internet users, those who are subject to digital exclusion are afforded fewer potential opportunities for information access and economic and social transactions, missing out on benefits relating to time, choice, convenience and cost. For those who are online the Internet is increasingly penetrating everyday life, and society as a whole functions progressively more on an expectation of access and engagement with new technologies. This runs the risk of deterioration in the availability and quality of offline services, disadvantaging those without Internet access.

Since those groups who tend to be digitally disadvantaged (for example people of lower income or educational level, people with disabilities, rural populations and the elderly) are also those which are subject to social exclusion offline, Warren (2007) describes the emergence of a digital vicious cycle whereby already vulnerable groups are disadvantaged further, which exacerbates the barriers to Internet access. This reflects the "knowledge-gap" hypothesis formulated by Phillip Tichoner in 1970, which suggests that "as the infusion of mass media information into a social system increases, segments of the population with higher socioeconomic status tend to acquire this information at a faster rate than the lower status segments, so that the gap in knowledge between these segments tends to increase rather than decrease" (see Warren, 2007). Rather than Internet access becoming more ubiquitous and available, closing gaps and offering opportunities for engagement to disadvantaged groups, as some digital optimists believe will happen, others warn against disenfranchisement and polarisation (Commission of the European Communities, 2005; Future Foundation, 2004; Warren, 2007).

Tackling the digital divide

From the discussion of barriers to digital inclusion it is clear that focusing on improving access and skills, whilst being necessary to addressing the digital divide, is not sufficient (Brabazon, 2005; Commission of the European Communities, 2005; Warren, 2007). The complexity of the issue dictates that a range of strategies is needed. As Dutton and Helpster (2007) conclude, the variation in reasons for not using the Internet given by ex-users in contrast to non-users, as well as differences between different demographic groups indicate a multi-faceted approach (see also Future Foundation, 2004; Communities, 2005). An EU report concludes that it is important to understand

how ICT is experienced in the context of people's everyday lives and how it impacts on social capital, individual well-being and quality of life (Commission of the European Communities, 2005). The report also recognises the "glocal" nature of the knowledge society, by which the access is to global knowledge but the application is local, therefore stressing the importance of local level initiatives as well as national and European strategy.

All EU member states have eInclusion policies which, in recognition of the link between social and digital exclusion, are implemented in the context of information society strategies as well as social cohesion policies (Commission of the European Communities, 2005). The involvement of a range of different stakeholders (business, government, education and research) is seen as necessary to facilitate greater digital inclusion (Communities, 2005; Foundation, 2004).

There are two broad complementary approaches to improving digital cohesion: strategies which target the whole population, and those aimed at the needs of those at particular risk of exclusion, for example lower income, unemployed, retired, older or disabled citizens. Policies should include actions which address problems of access, for example subsidies for equipment and access costs for people on benefits or low incomes, home Internet access leasing schemes, telephone intermediary schemes (see Blythe & Monk, 2005) and the creation of public Internet access points in places such as libraries, community centres, cybercafés, as well as mobile units. For those who have physical, sensory or learning difficulties which would impede their use of mainstream public facilities, there is a need to stimulate and harness technological advancements to provide alternatives for example assistive or adaptive devices and software, user friendly web formats (which comply with Web Accessibility Initiative guidelines, see WAI, 2007) and Internet access via digital television. Strategic publicity and ongoing evaluation of initiatives to improve Internet access for the digitally excluded is needed to ensure effective outcomes (see Pilling et al., 2004).

Education is a key area of policy in terms of raising awareness and developing computer literacy, through initiatives such as the provision of Internet connections to all educational institutions, and the integration of ICT into educational curricula at all levels, including Lifelong Learning programmes. Policy makers should also address mental barriers to digital inclusion, aiming to motivate and interest users by developing digital content which is relevant, attractive and easy to use for a range of different needs.

The Future Foundation report (2004) stresses the importance of involving disengaged groups in the design of new technology and recommend that technology must become more affordable and interfaces should be "genuinely intuitive or invisible – requiring no extra skills" to create a more digitally inclusive society (Future Foundation, 2004, p4).

Faced with limited resources for social development, and perhaps given its intangible nature, it may be argued that bridging the digital divide is, within some nations, a low priority for policy makers (see Future Foundation, 2004; Guo et al., 2005). However the cyclic link between digital and social exclusion should not be ignored. As Guo et al (2005) suggest it is perhaps not an exclusive choice to be made. Whilst improving digital inclusiveness in itself cannot solve the problem of social deprivation (and nor indeed can tackling social divides bring about digital participation for all), it has an important role to play in the pursuit of social advancement.

The Internet and social life

There is much debate as to the effect of Internet use, in particular CMC, on social life and wellbeing. Comparing it to earlier developments in technology Manasian (2003, p4) concluded that the Internet would:

> *"…change almost every aspect of our lives – private, social, cultural, economic and political. In some areas, the changes may be marginal, but in most they will be profound, and unprecedented. This is because new electronic technologies deal with the very essence of human society: communication between people. Earlier technologies, from printing to the telegraph… have wrought big changes over time. But the social changes over the coming decades are likely to be much more extensive, and to happen much faster, than in the past, because the technologies driving them are continuing to develop at a breakneck pace. More importantly, they look as if together they will be as pervasive and ubiquitous as electricity."*

The media provides us with opinions and stories of the Internet and its effects, mostly negative ones, on society; tales of addiction, isolation, neglect of the real world, deception, crime, antisocial or subversive behaviour, the attainment of support and a sense of belonging to otherwise marginalised groups, and relationships, including romantic ones, which have flourished from online meetings or reunions.

There seems no doubt that the Internet has significant potential to affect social life and wellbeing, but there is disagreement as to whether this is for the good or the bad. As the ensuing discussion will demonstrate, the issue, like any social phenomenon, is complex. Many scholars conceptualise the relationship between Internet technology and society from a position of social realism concluding that the technology shapes and is shaped by social life (Lea & Spears, 1995). *Adaptive structuration theory* proposes that the use of a technology may change from its intended purpose as people interact with it and structures emerge (see Christopherson, 2007). An example of this is the rapid growth in the use of mobile phones for text messaging compared to its use for spoken interaction.

In his introduction to the field of CMC, Thurlow et al (2004) characterise communication as dynamic, transactional, multifunctional and multimodal. Communication is the means by which we express our identities, establish and maintain relationships, and build communities. What then are the implications of the new method of communication provided by the Internet for these important facets of human society? To understand the relationship between the Internet and social life requires consideration of the characteristic qualities of CMC, and theories of interpersonal dynamics in the online setting.

The distinct nature of CMC

As Bargh and McKenna (2004) point out, the Internet combines many of the features of the technological advances which precede it. Like the telephone it can be used for person-to-person communication; like radio and television it can function as a mass medium. It can also serve as a seemingly infinite source of information and contact with a diverse range of people over great distances. However there are other essential characteristics which distinguish the Internet from other forms of communication, including face-to-face communication. Regarding text-based Internet communication which is the predominant form of online interaction and is the main focus of this research, there is an absence of the nonverbal features of face-to-face communication such as posture, facial expression, gestures, eye contact, and tone of voice. These are aspects which are crucial to the overall meaning of a verbal utterance, adding nuance, context, emotion and undertone to the words which are used. They are also important in managing interpersonal communication, facilitating turn taking, topic maintenance and transition, conversational repair and clarification. Also absent in CMC are cues to personal characteristics such as physical attractiveness, social status, colour of skin and gender. Indeed it is possible to

be relatively anonymous on the Internet, particularly in electronic group situations such as newsgroups or chat rooms. It is therefore easier to assume the role of a passive observer of communication online than it would be in other interactive situations. This is known as "lurking."

Other dimensions by which CMC may be distinguished from other forms of communication are its level of synchronicity, speed and permanence. Forms of electronic communication such as bulletin boards and email do not require communicative partners to be online at the same time. Whilst instant messaging and chat rooms do involve simultaneous online engagement, the rate of exchange of the text-based messages is slower than spoken forms of communication. However CMC is faster than other forms of written communication. It is arguably more permanent than spoken communication and yet has "perceived ephemerality" (Sproull & Kiesler, 1991, p41) compared to other written forms of communication.

The Internet is not a single communication technology, but a collection of technologies, in a state of continual evolution, one which incorporates qualities from other media, and yet lacks other aspects traditionally regarded as crucial to human interaction. There are many factors to consider in relation to how people interact over the Internet (see Thurlow et al., 2004):

- the type of channel (for example email or web-page based such as bulletin board)
- the mode of communication involved (text, graphics, audio-visual or multimedia)
- the number of participants involved (person-to-person or group)
- the length and nature of the relationship between the participants
- the topic and purpose of the interaction
- the degree of synchronicity of the communication channel
- the attitude and experience of the participants
- the degree of privacy
- the degree of moderation over the interaction

On this basis I shall now discuss theories and empirical evidence pertaining to the effects of the Internet on interpersonal dynamics and relationships, and individual wellbeing.

The Internet and interpersonal dynamics

Initial research and theory on the interpersonal dynamics of CMC was quite negative, focussing on the relative lack of social cues on the Internet, with little consideration of the active role of the individuals involved in communication. However, as the Internet has changed in its structure and capabilities, penetrating further into the everyday lives of more and more people, theoretical premises have been revised and refined, bringing the evolution of new more sophisticated and complex theories, which incorporate concepts of adaptation, personality and motivation (McKenna & Seidman, 2005). There has also been a move away from early deficit approaches to CMC which compared online communication with the "gold standard" of face-to-face communication. I shall now give a brief overview of the main theories of interpersonal dynamics via CMC which have been used to predict or explain its impact on social life and wellbeing.

Deficit approaches to CMC

Initial theories which were applied to CMC suggested that it lacks the important qualities of face-to-face communication and so will always be inadequate and may have negative effects on its users and their interactions. Such models predict that CMC is not well suited to social communication due to the absence of nonverbal cues which modify meaning, convey emotion, provide indications of status and role, and support communicative fluency. Online communication would therefore be impersonal, and possibly harmful; asocial and antisocial (see Thurlow et al., 2004, p46) .

According to the theory formulated by Short et al (1976), *social presence* is the level of awareness a communicator has for the presence of an interaction partner. As such, face-to-face communication has the highest degree of social presence. The theory proposes that having fewer visual and auditory cues reduces social presence in an interaction such that it becomes less personal and more task-orientated. Social presence theory has been used to predict or characterise CMC as impersonal. Caplan et al (2007) however, argue that although social presence is influenced by the number of communication cues a medium can convey, primarily it is determined by users' perceptions, implying a more sophisticated relationship. A reduced social presence account of CMC has been criticised for being based on studies of technology, such as telephone communication, which predated the use of computers for communication (Thurlow et al, 2004, p50).

The *reduced social cues* hypothesis is based on the work of Kiesler, Siegel and McGuire (1984) and was concerned specifically with CMC and its negative effects on group processes. The main predicate of the reduced social cues model is that the lack of social cues online makes interactions between people much more difficult to manage, such that conversations are less easily regulated, more effortful and lack fluidity. The absence of nonverbal cues could compromise efficacy of communication due to misunderstandings and conversational breakdowns, setbacks which would be harder to locate and repair due to the lack of immediate, visual and auditory feedback (Collins, 1992). The reduced social cues theory also posits that CMC participants will experience feelings of anonymity and be less sensitive to the thoughts and feelings of others. Accordingly communication becomes more task-focussed, more self-absorbed and uninhibited, and the perceptions of others online may become depersonalised. Therefore group norms and social influences are undermined increasing the possibility of extreme, aggressive or inappropriate behaviour. A hypothesised benefit of the reduced social cues model is that "scant social information in these technologies might cause status equalisation in groups" and hence a more even distribution of participation (Dubrovsky et al., 1991, p119). This would be particularly pertinent for the empowerment of traditionally marginalised groups (for example women, members of minority groups and people with disabilities).

However Thurlow et al (2004, p61) criticises this model of online behaviour as too technologically deterministic, pointing out that it cannot account for the fact that more impoverished forms of communication such as letter-writing do not provoke aggressive behaviour. As will be discussed in the next section, the *social identity model of deindividuation effects* (SIDE model) draws on evidence that adherence to group norms does occur in online groups. Investigations by Joinson (1999) produced evidence to contradict the key role of anonymity in producing disinhibited behaviour online. People scored significantly lower on scales of social anxiety and social desirability when completing these measures online compared to those who completed paper-and-pencil versions, implying that disinhibition in the form of enhanced self-disclosure occurred on the Internet. However this effect was not diminished by conditions of non-anonymity, in which people were asked to include their name and other personal identifying details with their responses.

Straus also presented evidence from two experiments which contradicted the equalisation phenomenon implied by the reduced cues hypothesis (see Straus,

1997). In one experiment she demonstrated a positive correlation between extraversion and participation rates amongst participants in a CMC group working task, and speculated that previous evidence of equalisation of participation may be an artefact of a ceiling effect on communication due to the limits on typing speed. In another experiment she found that the amount of communication in CMC was limited for all group members compared to face-to-face controls, restricting contributions from the most and the least dominant participants, thereby casting doubt on the assertion that CMC creates equalisation because it enables inhibited people to be more assertive. I shall discuss the issue of reduced social cues in relation to participation of marginalised groups further when I discuss the perception that CMC breaks down attitudinal barriers faced by people with disabilities

According to *media richness theory* (Daft & Lengel, 1984) there is an optimal match between the complexity of a communication task and the effectiveness of the medium which can fulfil the task: the more complex the task the richer the medium required. The richness of a communication medium is determined by its bandwidth (the ability to transmit multiple cues), the availability of immediate feedback, the potential for natural language use, and its personal focus. The model predicts that personal intimate messages are more complex and therefore cannot be successfully transmitted by the poorer medium of CMC, which is more suited to more straight forward task-focussed communication. Once again this is a model which pertains to earlier communication media and which has been adopted for CMC. According to Walther and Parks (2002) observational and experimental studies (for example Dennis & Kinney, 1998; Markus, 1994) do not support the predictions made on the basis of media richness theory, showing that lean media such as CMC can be used to accomplish complex tasks.

Walther (1992) points out that empirical evidence to support "cues filtered out" theories is largely based on experimental or case studies, of short duration, in the limited domain of synchronous task group conferencing (for example Kiesler et al., 1984) and in some cases organisational email (for example Sproull & Kiesler, 1986). Although findings confirmed the predictions of these models that online communication would be focussed on tasks with fewer instances of socially orientated communication, such findings failed to generalise to everyday life. Field studies of chat rooms, newsgroups, and MOOs have revealed that healthy relationships do develop online, complementing face-to-

face relationships (see for example Parks & Floyd 1996; Parks & Floyd 1998; Peris et al., 2002).

McCormick and McCormick (1992) analysed email generated over a six month period on a college system catering for approximately 700 undergraduate students and found that less than half of the messages were work-related, the rest serving purely social functions. Over a quarter of the messages were highly intimate in nature, and there was "unexpectedly little evidence of "flaming" or hostility and social inappropriateness". In parallel to the observational part of this study, 212 students volunteered to complete a questionnaire, 51% of whom cited socialising as their primary reason for using email. I shall now examine models which predict and explain social communication online.

Compensatory models of CMC

As CMC grew in its application and availability, theoretical perspectives evolved which acknowledged the active role played by those who used it, and attempted to address the mismatch between previous theories and empirical findings. It was proposed that individuals engaged in strategic cognitive deliberation and communicative behaviour to compensate for media limitations. There is a basic need for social bonding regardless of the communication medium, such that people adapt and use the cues available to them to fulfil this communication imperative (Thurlow et al., 2004, p51). In some instances this may result in interactions and relationships which are in some respects superior to those of the face-to-face situation.

Walther (1992) rejected the notion that a lack of nonverbal cues restricts the ability to communicate on a personal psychologically close basis and developed the *social information processing* model of CMC interaction. The theory posits that people exchange social information via the content, style and timing of their textual online messages, and therefore CMC and face-to-face communication are equally appropriate for the formation of close relationships. However, in CMC this takes time due to the process of adaptation, as well as the slower rate of exchange associated with a restricted bandwidth and the slowness of typing and reading relative to speaking, looking and listening. The importance of time explains why many experimental studies support deficit approaches to CMC whereas field studies frequently do not. Walther supports the social information processing model with evidence from experimental and comparative studies of CMC and face-to-face groups carried out over extended periods of time, as well as a meta-analysis of previous CMC research which

demonstrated a significant effect for time limitation (for an overview of relevant research findings see Walther and Parks, 2002). Research also suggests that certain relational and contextual factors can positively affect the interpersonal nature of CMC, specifically, the existence of a previous interaction, anticipation of future interaction, high expectations, and motivation and the use of emoticons (see Walther and Parks, 2002).

Reports of surprisingly close online friendships, as well as romances and closely knit online groupings, prompted Walther (1996) to develop and test the idea of *hyperpersonal* communication in CMC, that is relationships online in some instances can actually be more friendly, sociable and intimate than would occur in a face-to-face situation. In the absence of visual and auditory social cues online, positive assumptions are made by participants about each other; additionally, because people are liberated from concerns related to physical appearance and nonverbal behaviour, as well as environmental distractions they are more able to focus on their inner self, their personal thoughts, feelings and ideals, with the result that self-presentation may be optimised. This is enhanced by the greater control which may be exerted over message construction; people can take the time to consider, edit and craft their messages to be more sociable, and may control their timing of self-revelations. As these processes occur reciprocally a feedback loop, of mutually reinforcing positive impressions conducive to intimate exchange, is created. In some circumstances, when time is limited and there is no expectation of future interaction, communicative participants may be intolerant of the shortcomings of CMC, developing negative perceptions of each other, and neglecting to use the positive adaptive capabilities such that the cycle of over-attribution results in "hypernegative" interaction (see Walther and Parks, 2002).

Empirical support for the hyperpersonal model includes person perception research in which partners in task-focussed CMC formed deeper impressions of each other, compared to face-to-face counterparts, albeit on a restricted range of attributes (Hancock & Dunham, 2001). Experiments carried out by Bargh et al (2002) indicated that individuals online were more likely to project ideal or hoped for partner qualities onto each other than those interacting face-to-face. Additionally, Walther and colleagues found that a long-term team of international students, who communicated with each other via email and who were provided with photographs of their communicative partners, reported less mutual attraction than a comparable team who communicated without this visual information (Walther et al., 2001).

Subsequent experimental work, conducted by Nowak et al (2005), explored the influence of synchrony and level of cues on people's perceptions of each other when collaborating within a small group via CMC over a five week period. Consistent with the hyperpersonal model, participants in low cue media perceived their partners as more credible and involved in the interactions, and reported more certainty and social attraction than those interacting via high cue media. The effect of synchronicity was to increase social attraction and self–reported involvement, whilst reducing perceived certainty. The suggestion is that interactivity is more easily perceived as occurring in real time communication.

The *social identity model of deindividuation effects* (SIDE model) also acknowledges the possibility that social communication can be enhanced by CMC (Lea & Spears, 1995). This model, which was applied to the group effects of CMC, posits that the lack of nonverbal cues online prompts participants to form feelings of connection to others based on *perceptions* of social category, shared interest or similarity. There is a shift in emphasis from an individual's personal identity towards group or social identity. In the absence of physical evidence of dissimilarity to contradict an impression of social connection to someone online, participants may perceive a stronger relationship than might otherwise occur. In contrast to the impoverished communication and disinhibited behaviour predicted by reduced cues theory, the SIDE model implies that CMC is essentially a more social communication medium than face-to-face communication due to enhanced social identity and group cohesion. Lea and Spears provide empirical evidence to substantiate the SIDE model (for overviews see Spears & Lea, R. Spears & Lea, 1994; Spears et al., 2002) based on experimental as well as naturalistic studies including an analysis of online groups which formed naturally in conjunction with a university course, and which showed that conformity to distinctive group norms emerged over time, norms of which differed from those characteristic of online communication outside of the group (Postmes et al., 2000).

Spears and Lea (1994) predicted that anonymity in CMC may be strategically used to meet personal goals and communication needs. A sense of group identity online may facilitate more effective cooperative working. Christopherson (2007) gives other examples and evidence of the strategic use of online anonymity, for example the use of an online forum to express opinions which are contradictory or unpopular to a majority view but which are endorsed by that particular group. There are also apparent gender differences in how

people use their anonymity in CMC, such that women are more likely to try and conceal cues to their social identity online. This is speculated to be a way of eliminating any power differential that may occur between men and women in a face-to-face situation.

According to Christopherson (2007) it is this strategic aspect of the SIDE model which determines whether the anonymity of CMC can contribute to prosocial or antisocial behaviour. As such it is not the medium itself which produces a particular behaviour, so much as the goals and behaviours of those who use it. I shall now discuss, the ways in which disinhibited behaviour can characterise online interactions.

The online disinhibition effect

According to Suler (2004, p321), "while online some people self-disclose or act out more frequently or intensely than they would in person." Compared to "real life" there is "an *apparent* reduction in concerns for self-presentation and the judgement of others" (Joinson, 1998, p44). In some cases this may be described as benign (Suler, 2004), for example people may disclose very personal information, their secret emotions, fears or desires, perhaps professing deep affection towards the recipient. Individuals may perform acts of marked generosity. On the other hand, online disinhibition may be characterised by toxic behaviour; the use of rude, offensive, aggressive or threatening language towards others; deception and lying; or involvement in activities in which they would not participate offline, for example crime or pornography. Collins (1992) also includes excessive use of the Internet to the neglect of other aspects of life as a form of disinhibited behaviour.

Suler (2004) points out that it is debateable as to whether all benign disinhibitory behaviour is positive. On the one hand personal growth may come from self- exploration and experimentation online, perhaps gaining support or new relationships. However there may be regret about revealing too much about oneself, leaving feelings of shame or vulnerability. There may also be ambiguity regarding toxic behaviour; for example using hostile language to another person may be a destructive, unproductive, compulsive, possibly cathartic act, but for some individuals it may constitute a therapeutic breakthrough.

Early deficit models of CMC interaction, particularly the reduced social cues hypothesis, were used to account for the antisocial aspects of online disinhibition as a result of the purportedly depersonalised nature of the online

communication format (see Collins, 1992). Although aspects of these models, particularly anonymity, can contribute to a theoretical explication of the online disinhibition effect, they do not explain the benign manifestations of disinhibition.

The SIDE model acknowledges the active role of someone who uses the anonymity of an Internet forum to engage in disinhibited behaviour which contravenes norms of their offline world, so long as the behaviour conforms to the particular norms of the online group (see Christopherson, 2007). However, according to Joinson (1998) the activation of social identity in preference to personal identity does not account for the excessive disclosure of self-relevant information which can occur as a result of disinhibition, nor the fact that disinhibited behaviour can still occur online when people are not anonymous.

Suler (2004) proposes that it is an interaction of six factors which create the online disinhibition effect: dissociative anonymity, invisibility, asynchronicity, solipsistic introjection, dissociative imagination and minimisation of status and authority. Suler provides a plausible account of this hypothesis, but does not provide any empirical supporting evidence.

By dissociative anonymity Suler refers to the phenomenon whereby people are unidentifiable affording them the opportunity to separate their actions online from their "in-person" lifestyle and identity, and thereby relinquishing themselves of the responsibility for their Internet-based behaviour. Invisibility online does not necessarily mean that a person is anonymous, however it may make someone less self-conscious. Also being unable to see the person with whom one is communicating means that one will not be inhibited by their nonverbal communication and responses. Collins (1992) also points out that in the case of hostile behaviour online, the fear of physical retaliation is eliminated. The only sanction which may occur via CMC is verbal retaliation, which may result in an escalation of the conflict which does occur online.

A lack of immediacy of reaction can also contribute to uninhibited behaviour, as people perceive that they will not have to deal with an immediate response to their actions. However Siegel et al (1986) found that when groups used email to tackle a decision-making task, compared to groups who used synchronous CMC there was less uninhibited behaviour such as strong and inflammatory language. The inference is that the reduction in pressure for an immediate reaction, allowing individuals time to consider and reflect, as well as the facility to more carefully construct and edit one's response, serve to lessen negative disinhibited behaviour.

Suler proposes that solipsistic introjection may occur in CMC whereby, in the absence of corporeal information and in conjunction with enhanced mental focus on text-based communication, self-boundaries are altered and an individual may feel their mind has merged with that of the online other. As such there may be a sense of "talking to/with oneself, which encourages disinhibition because talking to oneself feels safer than talking with others" (Suler, 2004, p323).

A process of dissociative imagination may occur in the CMC situation such that individuals perceive that what occurs online is not real and therefore absolve themselves of any accountability for their actions online.

According to Suler, the traditional philosophy of the Internet is one of democracy, in which everyone is an equal. It was designed for the sharing of ideas and resources and has no centralised control, evolving organically with seemingly no end to its potential. This philosophy, as well as the minimisation of social status cues online, means that people will feel less constrained by authority.

Ben-Ze'ev (2005) proposes ways in which intimacy and self-disclosure may be facilitated by online interaction, pointing out that in the absence of other sources of personal contextual information people will need to reveal more about themselves in order to get to know each other.

The models discussed so far have focussed on the technical features of the Internet as a communication medium and how they may affect interpersonal communication and behaviour, which have implications for individual wellbeing, relationships with other people and the wider community. However in order to fully understand the effect of the Internet on psychosocial functioning it is essential to consider also the personal characteristics of the users as well as their preferences, needs, motives, activities and behaviours when online.

Uses and gratifications theory

Uses and gratifications theory originated in the 1970s, in an attempt to explain the uses and functions of mass communication for individuals, groups and society in general, but has also been applied to interpersonal communication research. At the core of the theory is the assumption that individuals actively seek out a particular communication medium to fulfil a certain cognitive or affective need (see Caplan et al, 2007). It is the effectiveness of this process which will determine the impact of CMC on interpersonal dynamics, individual wellbeing and social functioning. As Joinson (2004, p472) puts it, the outcome

is "a product of the motivated choices users make, rather than necessarily an outcome of media use per se."

O'Sullivan (2000) drew on an impression management model to understand how people use different communication media, proposing that individuals make choices according to the image they want to project, and this will vary according to personal goals and contextual variables. 136 undergraduate students were asked about their preferences for mediated communication (telephone, answer machine, email, letters) in relation to face-to-face communication, in four types of situations which either threatened or supported self-presentation for themselves or their partner (labelled as confessing, accusing, boosting, or praising). The results indicated that respondents preferred mediated channels when self-presentation, particularly their own, was threatened, whereas face-to-face communication was preferred in situations supportive to self-presentation. O'Sullivan proposes that the narrower bandwidth of some media creates greater ambiguity which may serve to protect preferred presentation of the self in threatening situations, whereas the clarity of face-to-face communication can support favourable presentation where there is no perceived threat. As such, in some instances, there may be a preference for a relatively narrow communication channel allowing greater control over self-presentation. Annette Markham's ethnographic account of virtual communities revealed that control was a key issue for participants, particularly in relation to self-presentation (Markham, 1998).

Various studies of CMC (Caplan et al., 2007; Flanagin & Metzger, 2001; Papacharissi & Rubin, 2000; Recchiuti, 2003; Stafford et al., 1999) have revealed a range of motives for its use which reflect its potential for both interpersonal communication (for example relationship development and maintenance, emotional support, persuasion, problem-solving) and mass communication (for example entertainment, escape, passing time and information seeking).

Recchiuti (2003) investigated how people differentiate their choices within the realm of CMC from a uses and gratifications perspective, which raises the issue of how features of a particular communication medium influence its use. 446 college students took part in a survey about their uses and motives for using email, instant messaging and chat rooms. Although all three types of CMC use were driven by three common motives (information seeking, interpersonal utility and entertainment), email emerged as a more instrumental form of CMC being used more for information seeking and task-related communication. On

the other hand instant messaging and chat rooms were used predominantly for socially orientated communication and entertainment. Convenience emerged as a unique motivation for the use of email, whereas a need for companionship, or to overcome loneliness, was a specific motivation for instant messaging as well as a desire for anonymity. Also pertinent to online communication were motivations to pass time (email and chat rooms) and to escape from work or other pressures (email and instant messaging). Recchiuti speculated that differences in synchronicity may account for these contrasting results.

According to the results of an interview study carried out by Stafford and colleagues (n= 112), the maintenance of personal relationships was found to be a very strong motivation for home email use (Stafford et al, 1999). This study also highlighted that another reason for use was the belief that it had particular beneficial attributes. Interviewees indicated that email was faster, easier and more conversational than conventional mail, and cheaper than telephone. Additionally the asynchronous nature of email emerged as an advantage, permitting people to communicate with friends or family who lived far away or in different time zones, or with those with whom they had insufficient time to keep in touch in person (see also Dimmick et al., 2000).

Some research suggests that motivations for CMC use may differ between light and heavy users. In a study of 576 college students, Leung (2001) found that heavy users of instant messaging were motivated by the need to express affection and sociability, whilst light users were motivated by fashion trends. On the basis of their survey of 279 college students, Papacharissi & Rubin (2000), found that individuals who used CMC to fulfil needs such as affection, inclusion, social interaction and control, spent more time online compared to those who used it for instrumental uses such as information seeking.

Uses and gratification research has also examined social, psychological and demographic antecedents which influence the motives and choices made regarding communication media. Relationships between life-stage, gender and patterns of Internet use have been discussed previously (see "Internet penetration and patterns of use.") However a discussion of the psychological and social predictors of Internet use and usage motives is pertinent to knowledge of CMC in relation to psychosocial functioning.

Personal differences in Internet use and motives

There is a growing body of research exploring the relationship between various personal characteristics and patterns of Internet use and usage motives, with

particular focus on dimensions of loneliness, shyness and extroversion. Although some studies have not identified associations between sociability or shyness and the social uses of the Internet (for example Madell & Muncer, 2006; Peris et al., 2002; Scealy et al., 2002; Stevens & Morris, 2007), others have produced results which do indicate differences in uses and motives between different personality traits.

One of the earliest studies into predictors of Internet use was carried out by Papacharissi and Rubin (2000) who explored Internet use, satisfaction, attitudes and motives in relation to individual willingness to communicate in a sample of 279 college students. Their findings indicated that those individuals who were less comfortable with face-to-face interactions, were more likely to use the Internet for social interaction, whereas people who were more comfortable with offline interactions tended to use the Internet more for instrumental purposes such as informational searching. The implication was that CMC was offering a functional alternative to those who had less confidence in face-to-face interactions.

Birnie and Horvath (2002) drew different conclusions from their survey of the frequency and intimacy of traditional and Internet social behaviours, as well as measures of sociability and shyness in 115 undergraduates. Sociability and the frequency of traditional social communication were positively associated with the frequency of Internet social communication. Also there was a positive relationship between the level of intimacy of traditional and Internet social communication. The authors concluded therefore that online communication was complementing or extending traditional communication rather than offering an alternative to shy individuals with less traditional offline contact. However shyness was positively associated with increased intimacy of online communication, but inversely associated with traditional communication intimacy leading Birnie and Horvath to speculate that the anonymity of CMC may create a forum in which shy people feel more able to express themselves or reveal feelings.

Further elaboration is provided by Recchiuti (2003) who found that, in particular, the use of chat rooms for task and social related communication was positively associated with loneliness and a lower level of satisfaction with offline interactions. Loneliness and also shyness were positively associated with the use of email for social related communication, including communication with people known only online, as well as the motive of escaping pressures, problems or responsibilities. People who found face-to-face communication

satisfying, however, were less likely to use email for these uses and motives. Regarding instant messaging, people who were shy, lonely or avoidant of communication, were more likely to cite reasons of companionship and anonymity for its use. Conversely, there was a negative association between these motives and satisfaction with face-to-face communication. Taken as a whole these findings imply that CMC can offer an alternative to people who are less comfortable with face-to-face communication, whilst its social uses are not strong motivators for people who are satisfied or rewarded by face-to-face communication. The potential for anonymity also emerges as a possible factor which appeals to less socially confident people.

Recchiuti's findings correspond with other research into the relationship between loneliness or shyness and CMC. In a survey of randomly selected newsgroup posters (n=568), McKenna et al (2002) found that people who were socially anxious or lonely were more likely to locate their "real me" on the Internet, a medium they could use to enhance self-expression. A survey of 169 university students conducted by Shepherd and Edelman (2005) found an inverse relationship between ego strength and the use of the Internet to counteract social anxiety.

A survey of 277 undergraduates, comparing the patterns of Internet use in lonely and non-lonely individuals, was carried out by Morahan-Martin and Schumacher (2003). Compared to non-lonely respondents, lonely people used the Internet and email more, and were more likely to use it for emotional support, meeting new people, finding others with similar interests, and to modulate negative moods. Additionally they were more likely to prefer online communication to face-to-face interaction, and to feel that online they opened up more, were friendlier and more themselves, and could make friends more easily. They were more likely to report that they had shared intimate secrets or pretended to be someone else when online. Their responses also indicated features of CMC which may contribute to its appeal; lonely people online were more likely to like the pace of communication, to find anonymity liberating and to have lurked.

Other studies have looked at individual traits pertinent to loneliness based on Eysenck's personality taxonomy. Again differences have been found in the patterns of Internet use between personality characteristics. In a study of 72 students at the University of Israel, Hamburger and Ben-Artzi (2000) found that for men extraversion was positively associated with the use of leisure services online and neuroticism was negatively associated with the use of information

services related to work or study. For women extraversion was negatively associated and neuroticism positively associated with the use of social Internet services such as chat rooms and discussion groups. The authors suggest that women may be more attentive to changes in their mental state and therefore be more likely to seek and find online a comfortable supportive environment to reduce loneliness.

Further investigations in this area were carried out by Amiel and Sargent (2004) who included the personality of psychoticism as a variable in their survey of the Internet use and motives of a larger sample of American university students (n=210). Extraversion was associated with the use of CMC to voice an opinion as opposed to seeking support or escaping loneliness. The Internet use of extroverts was generally more concerned with instrumental or goal-orientated functions, such as research and music downloads. People who scored highly in neuroticism were more likely to use the Internet to fulfil a need for information (including news as well as work-related) or a sense of belonging. However, in contrast to the sample in Hamburger and Ben-Artzi's study, they were relatively uninterested in text messaging or online discussions, which the authors speculated may be a result of the anxiety and misapprehension which characterises neuroticism. Differences in sample size and national demographic factors should also be considered when comparing the two studies. High scorers of psychoticism showed more interest in "deviant, defiant and sophisticated Internet applications," for example pornography and file sharing.

Overall from the research so far it seems that there are variations in patterns of Internet use and motives related to personality differences. In particular people who are more socially confident seem to be more concerned with instrumental Internet use, and use online communicative functions as an extension of their traditional interactions. On the other hand, individuals who are less confident or fulfilled by traditional forms of communication may be using the Internet as a means of compensating for these deficiencies. It should be noted however that the research discussed so far has focussed largely on samples of undergraduate students, and has tended to examine cross-sectional associations between measures of personal characteristics and patterns of use, therefore limiting conclusions in terms of generalisation and the direction of relationships. Rather than the Internet offering an alternative form of interaction to lonely or socially under-confident people, some (for example Kraut et al., 1998) have argued that higher levels of use may actually cause loneliness and social withdrawal

due to the replacement of real-life relationships with Internet-based interactions which, according to reduced cues hypotheses, are impersonal and unsatisfactory. There will be further discussion of this later (see "CMC and personal relationships.") However those studies which asked users about their motives (for example Morahan-Martin & Schumacher, 2003; Shepherd & Edelman, 2005; Recchiuti, 2003; Papacharissi & Rubin, 2000) imply that there are aspects of the Internet which may appeal to lonely or socially under-confident people.

I shall now discuss some studies which may illuminate the relationship between CMC and psychological and social characteristics, and which offer explanations for this connection.

Theoretical perspectives on CMC and personality

Goby (2006) investigated the degree to which personality differences, based on the Myers-Brigg Type Indicator (MBTI) dimensions, affected choice of offline or online communication for various types of social interaction. Their results indicated differences between personality types in their willingness to embrace online communication. There was a strong correlation between communication choice and introversion/extraversion, such that extroverts were more likely to opt for offline communication. There were also correlations between communication choice and other personality dimensions. People who were thinkers (that is tended to come to decisions through logical, consistent, detached reasoning) were more likely to choose CMC than feeling types (people who made decisions by associating or empathising with a situation, taking into account the needs of all interested parties and the relative values and merits of issues). Individuals who had a judging attitude (preferring organisation, planning and closure) as opposed to one of perception (who are more spontaneous and reactive to incoming information) were more likely to choose CMC. Goby suggests that for people who are more focussed on incoming information (perceiving), or are less analytical (feeling) or more oriented toward the outer than the inner world (extroverts) a "cues filtered out" perspective may account for their lower level of engagement with CMC. Conversely people who are more oriented to their inner world (introverts), less spontaneous (judging) or more analytical (thinkers) may be better equipped from a social information processing perspective to assimilate and successfully manipulate online communicative information.

A different range of personality variables ("The Big Five") in relation to the extent of Internet use was investigated by Engelberg and Sjoberg (2004) as well as work/life balance, emotional intelligence, personal values and loneliness. They did not find a relationship between Internet use and measures of openness to experience, conscientiousness, extraversion, neuroticism, or agreeableness. However people who scored high on loneliness or idiosyncratic values were more likely to be frequent users of the Internet. There was also a weak but significant negative relationship between use of the Internet and measures of work/life balance and emotional intelligence. The authors suggest that "A greater sensitivity to emotional cues may strengthen the sense of reward that comes from interaction face-to-face, which would, therefore, be preferred to the rather shallow interactive character of the Internet."

Stritzke et al (2004) conducted a systematic investigation of the relationship between shyness and CMC use based on *self-presentational theory*. According to this hypothesis, shy people are not, or believe that they are not, sufficiently adept at social interactions. They perceive a discrepancy between the way they present themselves and the way they desire to present themselves. There is an anticipation of social incompetence and rejection, such that there is increased sensitivity to any nonverbal or verbal feedback which could be interpreted as negative or inhibitory. Therefore, with fewer feedback cues evident in CMC, shyness should diminish. Additionally there are fewer cues to social status online and therefore less impact on the shy person of perception of social dominance. Communication via text also affords greater anonymity and control over message construction such that the discrepancy between perceived and desired self-presentation may be minimised. Evidence supporting a self-presentational theory of shyness was obtained from a survey of 134 university students which found that self-reported measures of shyness were significantly reduced in online contexts compared to face-to-face situations such that there was no significant difference between shy and non-shy individuals online (Stritzke et al, 2004). There were also significant reductions online for shy people in their ratings of rejection sensitivity, and increases in ratings of relationship initiation and self-disclosure, aspects which according to self-presentational theory are affected by non-verbal and social cues, and control over message construction.

Leary (1986) conducted experiments which indicated that where there is a possibility of external interference with communication, self-presentational anxiety is reduced, which he surmised was a result of any problems of social

interaction being attributed to external factors rather than personal incompetence. The reduced bandwidth of CMC could be one such alleviating factor.

Joinson (2004) found evidence suggesting that people with low self-esteem may also protect themselves from negative feedback by using email, particularly when there was a higher chance of rejection. 265 participants ranked communication media in order of preference across different communication scenarios posing interpersonal risk, with varying chances of rejection. Low self-esteem users showed significantly higher preference for email, whereas high self-esteem users preferred face-to-face communication. There was also a positive relationship between the strength of the possibility of rejection and preference for email over face-to-face communication. As well as the visual anonymity of email, Joinson also highlights its asynchronicity as pertinent in enhancing control over self-presentation, and the pace and content of interaction.

Further evidence for self-presentational theory in relation to shyness and CMC, was provided by semi-structured interview data from people who took part in two synchronous social text-based environments: MOOs and Internet relay chat (Roberts et al., 2001). Shy individuals reported that they found social communication easier online and were less inhibited in their behaviour, and attributed this to various factors: not seeing the other person, being unseen themselves, being anonymous, a perceived lack of judgement from others, reduced fear of rejection or negative feedback. There was a sense that one was judged on one's words rather than personal attributes such as physical appearance, gender, culture, social status. Scott (2004, p99) conceptualised the Internet as a "cybershell" providing "a safe retreat from the social gaze."

McKenna et al (2002, p10) also attribute the attraction of CMC to shy individuals, to its lack of "gating features", that is, "easily discernible features such as physical appearance (attractiveness), an apparent stigma such as stuttering…., or visible shyness or social anxiety," which may militate against relationship formation. They carried out an experiment in which individuals interacted with each other for twenty minutes on two occasions, once over the Internet and once face-to-face, unaware that they were meeting the same person each time. Results showed that dyads liked each other substantially more when interacting over the Internet than when interacting face-to-face. However, a survey of 666 undergraduates carried out by Stevens and Morris (2007) produced results that may modify perspectives on gating features.

Students who were highly anxious were nine times more likely to endorse the use of webcams in relationship maintenance. The authors speculate that even though participants can see each other, webcams may still act as buffers, such that some features of anxiety, for example trembling or blushing, may be less obvious

A six month longitudinal study carried out by Roberts et al (2001) found that not only did online interaction provide a forum in which shyness was reduced, but there was also a significant reduction in offline shyness for highly shy individuals. The authors proposed that reduced public self-awareness and the perception of safety online are liberating for shy people which results in disinhibited, more sociable interaction and opportunities to try out new behaviours. With less visual, seemingly negative feedback, and the possibility of positive reinforcement, self-perception of social competence may improve with the possibility of generalisation of behaviours to offline contexts. Additionally some online relationships may evolve onto offline associations, which will also support the transfer of newly found skills to other contexts.

Before moving on to discuss the wider implications of CMC for personal relationships and individual wellbeing, a brief summary of the discussion so far would be valuable. Early reduced cues theories predicted that participants' attention would be diverted away from the social and emotional aspects of communication, thereby compromising, or even damaging interpersonal relations (see Walther and Parks 2002). Alternative views however indicate that there is a communication imperative, and as such people may, depending on social context and with sufficient time, adapt to the Internet as a communication medium. Indeed there are instances in which the lack of nonverbal cues may be personally liberating for participants in terms of loss of inhibitions, control over self-presentation and interactions, and heightened interpersonal dynamics. Disinhibited behaviour online may be prosocial or antisocial in its manifestation.

Evidence suggests that the effects of CMC depend largely on the personal characteristics of participants, their goals and motivations, which will influence their communicative choices. It is this which no doubt explains the contradictory or variable outcomes evident in CMC research. This is not to dismiss the contribution of the particular qualities of the Internet as a communication medium, which are also implicated in the complexity of the phenomenon; in particular the lack of nonverbal information, potential anonymity, and different pace. With consideration of all aspects of CMC as a

guide, that is the interaction between the particular features of the communication medium, the goals and needs of the communicators, and the social context, I shall now review the commentary and research findings with respect to personal relationships and individual wellbeing.

CMC and personal relationships

Studies of the quality of online social interactions and relationships have drawn mixed conclusions. Some dovetail with reduced cues theories of CMC and imply that online interactions are inadequate compared to more personal forms of communication. 39 students completed ratings of all types of communication episodes which occurred over a four hour period (Cummings et al., 2002). Email was rated as inferior to face-to-face or telephone conversation for the purpose of maintaining personal relationships. The same authors in an earlier study of 979 employees of a multinational bank found that email was perceived as significantly inferior to face-to-face communication or the telephone for maintaining relationships (Cummings et al., 2002).

From their survey of a representative sample of the Israeli adolescent population (n=987), Mesch and Telmud (2006) found that the closeness of a friendship was related to its duration, the social similarity of the individuals involved, and the degree to which issues and activities were shared. Online friendships were perceived as less close compared to in person friendships due to the lack of joint activities and relatively superficial nature of discussions, as well as their relatively short history.

Conversely McKenna et al (2002) found that people who disclosed personal information about themselves via CMC were highly likely to form close lasting online relationships, which may become successfully integrated into their offline lives. The authors claimed these relationships to be comparable to in-person relationships in terms of stability and level of closeness, but were faster in their rate of development. Additionally, experiments carried out by the same researchers showed that participants interacting with a new acquaintance over the Internet were more successful in conveying aspects of their "true selves" to each other, compared to those who met face-to-face (Bargh et al., 2002). Online participants were also more likely to project their ideal image of a close friend onto their partners. Taken together these findings imply that the anonymity and lack of nonverbal cues of CMC may promote hyperpersonal interaction, enhance self-disclosure, and remove "gating features" which may deter the formation of face-to-face relationships. McKenna and Bargh (2000,

p68) hypothesise that some relationships formed online may therefore be "deeper, more stable and longer lasting than those formed in the real world environment in which physical attractiveness and proximity are such powerful constraining forces."

Probably the most controversial issue regarding the social effects of the Internet is that of the effect on close relationships such as those with family and friends. Kraut et al (1998) conducted a longitudinal study in which 73 families (169 people) who did not have a home computer were given one as well as Internet access. Follow up at two years revealed small but significant increases in reported depression and loneliness, as well as significant decreases in communication with family members, and size of social circle, as functions of the amount of Internet use. The authors referred to the seemingly negative effect on psychosocial outcomes of an apparently "social technology" as the "Internet paradox." This study lent support to the notion that virtual relationships would supplant real-life social relationships, with a decline in quality and detrimental effects on psychosocial wellbeing. There are also parallels with reduced cues theories of online interpersonal dynamics. Although this was a much publicised study, it was criticised for using two convenience samples, without a control group (see Shapiro, 1999). It was also suggested that the study samples were inadequate in that they either had a higher than average level of social contact at the outset (families which included an adult member of a local community development organisation board of directors), or were at a life-stage associated with a potential decline in social contact (households including a student who left college over the course of the study).

Later studies have not revealed declines in social and family involvement, and actually imply that the Internet may be a medium for maintaining or augmenting existing social relationships, one which offers greater potential for the cultivation of new relationships.

A series of randomised telephone surveys of larger more representative samples of the US adult population (ranging in size from 557 to 2500 respondents) conducted between 1995 and 2000 (Katz et al., 2001) indicated that Internet users were more likely than non-users to communicate with other people via other media (in particular by telephone), to meet with friends more, and generally have more interaction with other people, although within a wider geographical area. By 2000, over one tenth of Internet users had made online friends, in many cases meeting them also in person. A similar proportion belonged to online communities.

From their two year study of Netville, a new suburban development of 109 homes in Canada, Hampton and Wellman (2002) concluded that residents with Internet access reported significantly more social contact than those without. Compared to a year before moving to Netville, non-wired residents generally reported that social contact had declined whereas there was virtually no change for wired residents, implying that the Internet can support and maintain relationships after a move to a new location. There was also a possible impact on building and sustaining relationships with new neighbours. Compared to residents without Internet access, wired residents knew the names of significantly more of their neighbours and spoke to them and visited them more often. Their relationships with other residents extended further in geographical terms. As well as interacting with their neighbours via email, wired residents telephoned them more often than those without Internet access. Hampton and Wellman concluded that rather than diminishing social contact and support, CMC puts people in touch with each other locally as well as globally, a phenomenon they termed "glocalisation."

Social network theory proposes that social behaviour and communication are influenced by the patterns of connections between people as well as the type of media available, the content and purpose of the communication and the prevailing social norms. Research indicates that the Internet supplements traditional social behaviour without necessarily increasing or decreasing it. A large scale survey (n=39211) found there was no relationship between the frequency of Internet use and the frequency of other types of communication (Wellman et al., 2001). There was a positive relationship between frequency of Internet use and the overall frequency of contact with family and friends. The implication is that CMC can keep people in touch with others near and far away, but traditional forms of contact (face-to-face and telephone) have qualities which cannot be replaced by the Internet. As Birnie and Horvath (2002) point out, "Like previous advances in communication technology, the Internet continues the process of connecting people participating in social networks and geographically dispersed people and organisations bound by shared interests."

The results of a daily tracking survey of Internet use which used a random sample of American adults (n=2200) also supports the assertion that email use does not detract from face-to-face or telephone contact, but that it is a more productive way of facilitating contact with large networks of people, both far away and locally (Boase et al., 2006). The average social network size was bigger for Internet users than non-users (37 people compared to 30).

In response to criticisms that the Internet has negative impacts on communities, and drawing on the results of their research, Wellman and colleagues (see Wellman, 2001; Wellman et al., 2002; Wellman et al., 2003) see the emergence of Internet-based communication as "facilitating changes which have been developing for decades in the ways people contact, interact and obtain resources with each other" (Wellman et al., 2002, p158). As a result of progressive social changes, including developments in transportation and communication, communities within the developed world have evolved into social networks rather than concentrated, relatively homogeneous groups of people. Individuals may be involved in various different networks, which have largely intangible spatial and social boundaries. The effect of the Internet in this process has been the emergence of person-to-person connections rather than place-to-place networks. The ongoing proliferation of places to access the Internet as well as the development of mobile phone and wireless technologies, means that people are less restricted in the locations at which they may connect with others in their various social networks. The effect is that individuals may personalise their own networks, a process Wellman et al (2002) refer to as "networked individualism." In this way, rather than destroying communities, the Internet has increased the opportunities for people to connect with each other, to expand and specify the social networks which characterise communities in developed societies.

Kraut and colleagues re-examined the "Internet paradox" three years after their initial study had implied that increased levels of Internet use were associated with increases in levels of depression, loneliness, and social disengagement (Kraut et al., 2002). Follow up of the participants found that earlier negative effects had dissipated. More frequent use of the Internet, especially email was associated with increased contact with both local and distant family members and friends. Kraut et al account for this change by observing that both the users and the Internet itself had changed since the first study. More people were now online, making it easier for them to contact closer family and friends. Additionally it could be that, in accordance with Walther and Parks' (2002) social information processing model, a period of adaptation had occurred enabling the reestablishment of relationships, which may have suffered transiently as the technology was introduced.

As a result of a second study comparing households who had recently purchased a computer and were given Internet access, with a control group who had recently bought a television, Kraut and colleagues added a caveat,

akin to the adage that "the rich get richer" (Kraut et al, 2002). This claim was based on the findings that extroverts who had high levels of Internet use were more likely to report increases in community involvement and self-esteem, and decreases in loneliness and negative affect, whereas introverts reported opposite effects. Additionally those who initially had more social support were more likely to increase their communication with family.

McKenna et al (2002), however, counter this claim and propose that the poor also get richer, pointing out that Kraut et al's study found that both extroverts and introverts showed increases in their local and distant social circles, as well as face-to-face contact with family and friends. Studies by McKenna et al (2002) suggested that although the friend-rich did indeed get richer as a result of their online interactions, socially anxious or lonely people who expressed their "true selves" online, also formed close relationships which became part of their offline lives, and in doing so extended their social circles and became less lonely or socially anxious.

Similarly, Katz and Aspden (1997) did not find any relationship between a propensity to make online friends and a wide range of measures of offline social connectedness and personality traits, concluding that the Internet deemphasises the importance of sociability and personality differences.

Sheeks and Birchmeier (2007) conducted a longitudinal study to elaborate on the work of McKenna et al (2002) and obtained results suggesting that individuals who obtained high scores on measures of both shyness and sociability seemed to form online relationships which were closer in nature and more satisfying than those formed by people who had lower levels of the two traits.

There is therefore an inference that people with low social confidence may benefit in particular in terms of their interpersonal communication and relationships in the online format. However, although Erwin et al (2004) found a positive relationship between time online and perceived benefits of social support, encouragement, confidence and friendship formation for socially anxious people, there was also a positive relationship between social anxiety and endorsement of the Internet as a means of avoiding feared aspects of face-to-face communication. They concluded that the benefits of CMC for socially anxious people may come at the expense of face-to-face social interactions which may be increasingly avoided thereby exacerbating the difficulties faced in this respect. If online relationships are deficient in strength and quality, there may be no gain for socially under-confident people.

Another study conducted by Gross et al (2002) found that socially anxious adolescents were more likely to communicate online with people to whom they were not close and on less intimate subjects, leading the authors to speculate that for these individuals replacement of in person communication by CMC may fail to sufficiently meet their interpersonal needs. This possibility was implied by the study conducted by Papacharissi and Rubin (2000). People who used the Internet primarily for information seeking, who tended to be those who were comfortable with face-to-face communication, were more likely to be satisfied with the Internet in meeting their needs compared to people whose use was orientated toward social communication, who were also more likely to be uncomfortable with face-to-face communication. However people who used the Internet for interpersonal communication had more affinity for it compared to those who were more motivated by informational use.

It seems from the discussion that, as in the offline world, some relationships may blossom on the Internet whilst others may flounder. Research examining the impact of the Internet on offline relationships has produced mixed findings, some implying that CMC may supplement real-life interactions, whilst others warn that it may replace them. Once again personal characteristics seem to be associated with different outcomes of online relationship formation and its impact on life offline. I shall now discuss the process whereby online relationships transfer to the face-to-face context.

Mixed mode relationships

Walther and Parks (2002) address the challenging issue of mixed mode relationships, citing examples of ongoing friendships or marriage which result from the transition of an online relationship to the 3D world, as well as those meetings which are disappointing and unproductive for future contact, and going on to explore theoretical perspectives to account for the variable outcomes of such relationships. According to social information processing theory, it is possible to get to know someone via CMC, therefore a face-to-face meeting would be superfluous to the relationship continuing. This perspective however is inadequate as research has shown that real life characteristics may depart from virtual impressions (Jacobson, 1999).

SIDE theory can account for the failure of relationships after face-to-face encounters, in that there will be a shift away from social identity towards personal identity and differentiation which may undermine social attraction. The model however does not explain the positive outcomes of mixed mode

relationships. According to Walther and Parks (2002, p551) the hyperpersonal perspective of CMC, whereby the absence of nonverbal information may serve to enhance self-presentation and perceptions of others resulting in increased intimacy, "does not bode well for the success of a shift to substantially less controlled information sharing…"

Walther and Parks (2002, p554) go on to discuss the importance of the correspondence between who people are and who they claim to be in mixed mode relationships. Typically, in face-to-face relationships there is a relatively strong warrant between the presented identity and the body's self, but this is limited online. They propose that the transition of a relationship to the offline world will depend on how warranting information is reconstructed during the process, suggesting that "incremental exchanges of higher-bandwidth cues, and other warranting information, act as break points for decisions about relational escalation or termination."

Walther and Parks go on to suggest three possible ways in which individuals may deal with face-to-face information in the context of perceptions of a pre-existing CMC relationship. One option, which they label as *indefinite postponement*, is that there will be certain degree of uncertainty associated with online relationships as a result of the absence of physical information, which means ultimate judgements will be delayed until such information is evident. In the event of a face-to-face encounter mutual evaluations, based on physical data, will be made in the way that judgements would be made in any first meeting. An alternative interpretive framework could be one of *irrelevance* or assimilation whereby, according to the strength of the online bond, new information is integrated into existing cognitive representations, with the effect that the availability of physical information is largely extraneous to the destiny of the relationship. The third framework is one based on *expectancy violations*. On meeting face-to-face comparisons are made between virtual and physical impressions. In the event that these largely correspond with each other, the relationship may not be fundamentally altered. If expectations are positively violated then an increase in attraction and intimacy may be expected. However the relationship may suffer if physical data negatively contravene preconceptions. Walther and Parks therefore suggest that if online partners attempt to lower each others' expectations prior to meeting in person, there is more chance the relationship will be sustained.

CMC and well-being

As already discussed, the use of the Internet for social communication has implications for interpersonal communication and relationships, albeit the association is one of complexity. In view of this, I shall now explore the relationship between psychological wellbeing and CMC. Gross et al (2002) suggest that the effect of the Internet on personal welfare depends on whether it meets people's needs in terms of social contact; whether it creates more opportunities for social connections, or alternatively, displaces real-life contact with isolating, unsatisfactory interactions online.

Weiser (2001) raised usage motives as significant to the psychosocial outcomes of Internet use and proposed a model in which Internet use and motives predicted level of social integration (based on community and social involvement, as well as strength of social support) which in turn predicted psychological wellbeing, as indicated by levels of loneliness, depression and life satisfaction. His study found that the number of hours spent online was weakly associated with psychological wellbeing, whereas there was a strong relationship between the predominant type of Internet use and psychosocial outcomes. Internet use which was driven by socio-affective regulation was negatively associated with level of social integration with negative effects on individual wellbeing, whereas its use for goods and information acquisition was positively correlated with social integration and favourable effects on wellbeing. Although structural equation modelling was used to indicate a causal relationship, it must be noted that this was based on cross-sectional data. Weiser concedes that in some circumstances Internet use may not impair social integration and wellbeing, for example allowing expression of socially sanctioned identities and contact with others who share that identity. However he interprets his research findings as endorsements of the potentially destructive effects of Internet use on social integration and therefore psychological wellbeing.

Evidence which questions the claim that the Internet negatively affects wellbeing emerged from a survey of 131 Internet users which indicated that most disturbances of psychosocial functioning had been evident prior to intensive use of the Internet (Modayil et al., 2003).

In contrast to the Internet paradox phenomenon, Morgan and Cotton (2003) found that increased use of the Internet for email, chat rooms, and instant messaging was associated with improvements in wellbeing as indicated by decreases in depressive symptoms, whereas increased use for less

communicative activities, such as games, shopping or research, was associated with an increase in depressive symptoms. Once again this was a cross-sectional study and therefore the direction of the relationship can only be surmised.

Additionally, Shaw and Gant (2002) tracked changes in measures of psychosocial wellbeing in pairs of individuals who communicated with each other over the course of five online chat sessions. They found that there were decreases in loneliness and depression and increases in perceived social support and self-esteem over the 4-8 week period of the investigation. This study was, however, small in terms of sample size (n=40) and lacked a control group.

As well as its impact on social relationships and therefore wellbeing, the Internet also offers communication in privacy which may potentially affect individual wellbeing (see Christopherson, 2007). The privacy online may serve three functions:

- *Recovery*: a sense of rejuvenation, refuge and relaxation as a result of active self-reflection
- *Catharsis*: the unhindered expression of thoughts and feelings
- *Autonomy*: bringing opportunities to experiment with new behaviours without fear of social consequences

Amichai-Hamburger (2005) suggests that the Internet can be therapeutic by providing a safe environment in which individuals can reveal and discuss traumatic and emotional experiences, therefore helping them to reduce their anxiety and assimilate the upsetting event.

Just as the discussion so far has indicated a complex interaction between Internet use, motives, personality, interpersonal dynamics and social relationships, the implications for psychological wellbeing are also complex. With particular reference to the role of personality, I shall now discuss the relationship between Internet use and five social phenomena which have implications for wellbeing: loneliness; liberation and empowerment; self-expression and identity; problematic Internet use; and social support.

Loneliness

As has already been discussed Kraut et al (1998) initially claimed that increased Internet use resulted in increased levels of loneliness and depression, and subsequently revised this assertion as applying to introverted individuals, extroverts being affected in the opposite direction (Kraut et al, 2002). The

limitations of the study have also been discussed. Moody (2001) went on to differentiate between emotional and social loneliness in his cross-sectional study of the Internet and wellbeing (n=166). The research findings supported the hypothesis that high levels of Internet use were associated with increased levels of *emotional loneliness* (which is based on a lack of intimate relationships) but lower levels of *social loneliness* (due to an inadequate sense of belonging to a community or group). Moody's supposition was made on the assertion that spending more time online and less time on face-to-face social relationships, of higher quality and strength than is possible online, results in emotional loneliness. Conversely the Internet may enhance the potential to create a network of like-minded others and therefore a sense of community, for which the weaker ties characteristic of online relationships are sufficient, with a reduction in social loneliness. The implication is that loneliness may result from high levels of Internet use despite the feeling of connection to a social group.

An alternative explanation for the relationship between Internet use and loneliness is that lonely individuals are actually more likely to be attracted to use the Internet due to its potential for choice and expansion of social networks, and the different nature of online communication which may offset any associated social interaction challenges; indeed the earlier discussion on personal differences in Internet use and motives (see "Personal differences in Internet use and motives") indicated differential patterns of use which imply that this may be the case.

Morahan-Martin and Schumacher (2003, p669) proposed that the relationship between loneliness and Internet may be bi-directional. Lonely users in their study were drawn to use the Internet to relieve loneliness, social inhibitions and negative affect, as well as to relax and pass time. However, although they reported enhanced social behaviour online, there was also interference with non-Internet social activity, and this was associated with guilt. According to the authors, "this suggests a vicious circle whereby lonely individuals go online to fill social voids and emptiness in their life, but their online time creates voids in their non-Internet social life and creates other real-life problems."

Liberation and empowerment

Amichai-Hamburger and Furnham (2007, p1035) describe the Internet as "a protected environment in which the users feel that they can take charge of their surroundings," and cite three aspects of the Internet which are potentially empowering, particularly for those who are less socially confident: anonymity,

control over the interaction, and the ease with which it is possible to find similar others. Studies imply that people who are socially anxious or inhibited are more likely to perceive the Internet as liberating. One study found that loneliness was positively associated with the likelihood of a respondent reporting that they were less inhibited, friendlier and more intimate online, and that online friends were a source of emotional support and fun (Morahan-Martin and Schumacher, 2003). Self-reports of shyness have been found to decrease online as discussed earlier (Stritzke et al., 2004; see also Yuen & Lavin, 2004), with some carry over to real life (Roberts et al., 2001). More time spent online was associated with perceived increases in self-confidence in socially anxious users (Erwin et al., 2004). Shaw and Gant's study (2002) of online chat sessions showed increases in self-esteem over the 4-8 week study period. Participants in an ethnography of virtual groups reported feelings of control and empowerment online (Markham, 1998). The Internet was a place where many people in the study felt they had more of a voice and the freedom to be more open without fear of judgement. It enabled them to feel more confident or allowed them to talk to people with whom they would find communication uncomfortable in other situations. There was also a feeling of control over the form and degree of connection which could be built up with others; more choice over the level of intimacy and extent of the relationship.

The potentially liberating effects of CMC have prompted some commentators to speculate on its therapeutic value in ameliorating shyness (see Amichai-Hamburger, 2005; Amichai-Hamburger & Furnham, 2007; Erwin et al., 2004; Roberts et al., 2001; Stritzke et al., 2004; Yuen & Lavin, 2004). As well as providing a medium for social interactions which may otherwise not occur, CMC could also be incorporated into treatment programmes for social anxiety which involve graded exposure to feared situations and rehearsal of social skills.

One particular way in which CMC might be liberating is in enabling self-expression, which has implications for sense of identity, particularly for stigmatised groups.

Self-expression and identity

Previous discussion has already highlighted that for some people, particularly those who are less socially confident, the Internet is perceived as a medium in which they may be more able to express themselves. Indeed in her research into shyness, Scott (2004) found that when participating in an email-based

discussion group, self-defined shy people could be extremely forthcoming and articulate, therefore shedding their shy role, and presenting a different identity.

Current theories of identity conceptualise it as socially constructed, multidimensional and dynamic, something which varies in different contexts, rather than a static phenomenon (see Thurlow et al, 2004). Like any other context the Internet offers the opportunity for the expression of particular facets of one's identity. There are implications for both personal and social aspects of identity. *Personal identity* relates to an individual's own self-concept as well as one's self-presentation to others, whilst *social identity* involves relationships to other people, how an individual perceives himself in relation to a group, and how others perceive him. For those people who find the Internet a comfortable place for self-expression there may be the potential to expand and enrich self-exploration and self-presentation. This may be achieved via CMC and also through the construction of personal web pages or blogs. Social identity may be affected online if, as has been discussed, people are less constrained by stereotypes associated with their physical appearance. Additionally, the greater potential to find similar or like-minded others has implications for group identification. Thus the Internet may enable people to explore different aspects of their identity, and to hold multiple identities simultaneously, with the potential to express individuality whilst belonging to a large significant group (Amichai-Hamburger & Furnham, 2007). Being "role rich" is associated with better wellbeing and greater life satisfaction, equipping people with more skills to face the stresses and changes of life (see McKenna & Bargh, 2000).

In their research into the Internet and identity, Bargh and colleagues (2002) approached self-concept from a Rogerian perspective (see Amichai-Hamburger, 2005, p33-36). Their experiments indicated that, compared to face-to-face communication, CMC was a more effective way by which individuals could convey their true-self qualities to other people. There was a high degree of correspondence between the characteristics which participants attributed to their "real me" prior to interacting online with a new acquaintance, and those which were used to describe them by their partners following the interaction. Research by Amichai-Hamburger et al (2002) indicated there were differences between different personality types and their perceived locations of self. Users of "chat" who scored high on measures of introversion or neuroticism were more likely to locate their real me on the Internet, whereas extraverts and non-

neurotic people were more likely to regard expression of their real selves as occurring via traditional forms of communication.

It could be argued that if some people locate their real selves online, then the assertion that the Internet is a poor substitute for the "real world" is unjustified. For these individuals the Internet could play a crucial part in maintaining their psychological wellbeing. Whilst Amichai-Hamburger (2005) acknowledges this, he adds caution to the concept of "real self", which is abstract in nature and "largely unknown to its host", questioning whether online behaviour can ever be interpreted in this way, or whether instead it is the sharing of intimate information in a seemingly safe environment with apparently empathic others. Whilst the Internet cannot transform the self, or create a completely separate identity to the offline world, it may provide a context in which some dimensions of the self are more evident than offline, and the self-concept strengthened (Amichai-Hamburger, 2005; Markham, 1998; Suler, 2004).

McKenna and Bargh (1998) hypothesised that people with stigmatised, probably hidden, social identities would be motivated to join online groups dedicated to that identity, due to the potential for anonymous participation with others whom it was hard to locate offline. Additionally they reasoned that such groups would be more important to its members than other types of online groups due to the opportunity for expression of the stigmatised identity, which would be reflected by the dynamics of online behaviour. The results of a series of studies indicated a significantly greater number of posts per person in negatively stigmatised groups (based on marginalised sexual interests or political views) on the Internet compared to non-stigmatised groups, and a correlation between the level of individual participation and the type of feedback (negative or positive) from other group members, not evident in other groups. Further investigations of the negatively stigmatised groups indicated that, compared to lurkers, active posters in the groups reported higher levels of self-esteem, self-acceptance and reduced levels of loneliness. They were also likely to have revealed their secret identity to family and friends as a result of their online group involvement. In this way the individuals were able to incorporate the group identity into their self-concept and address internal conflicts between the self and their everyday experiences.

Problematic Internet use

As had happened with the emergence of other new media technologies throughout the twentieth century, the "online rush" of the 1990s brought with it

fears for society in terms of excessive use and addiction (see Thurlow et al., 2004, p150). Such claims which have been particularly evident in the popular press raise several questions. Firstly, does Internet addiction actually exist, or is there another conceptualisation for excessive and compulsive Internet use? If it does exist, then what are people addicted to? What underlies the addiction, is it the technology itself, or the choices which people make about social interaction online and offline?

In line with a broadening conceptualisation of addiction as pertaining to a diverse range of behaviours (for example gambling, sex, exercise, shopping) rather than merely focussed on physiological dependency on an external substance, Griffiths (1998b) argued for the potentially addictive nature of technology, including the Internet, due to the alternative realities users may experience online, as well as feelings of immersion and anonymity, and possibly an altered state of consciousness, which may be psychologically rewarding. However Davis (2001) prefers to draw on definitions from the DSM-IV (American Psychiatric Association, 1994) whereby addiction refers to a physiological dependence. Therefore recent research has tended to use the terms problematic or pathological Internet use (PIU) to describe patterns and levels of Internet use which result in negative consequences for family, social, or occupational welfare. Davis makes a further distinction between PIU which is specific, and that which is generalised. Specific PIU concerns overuse of a particular Internet function, independent of other Internet behaviours, for example gambling, pornography, or auction sites. The excessive use is content specific and the Internet is seen as a vehicle for the expression of a dependency which would exist in its absence. In contrast, generalised PIU pertains to the negative consequences of multidimensional Internet use, often associated with social functions such as online chat or email, or a drive to waste time online without a clear objective.

Although the terms problematic or pathological Internet use are increasingly used by researchers, there is as yet little empirical evidence for the existence of such disorders. Many studies have been limited by the use of self-selected or self-defined samples as well as the use of clinical criteria which lacked validity (Griffiths, 1998b; Morahan-Martin & Schumacher, 2000). They do, however, provide descriptive information about excessive patterns of Internet use, which have been elaborated by detailed case studies (see Griffiths, 1998a; Young, 1996). Caplan (2002) designed an instrument to operationalise Davis' generalised PIU construct, which was administered to 386 students and proved

to be reliable and valid. Factor analysis identified seven cognitive or behavioural symptoms associated with PIU (see also Caplan, 2003, and Davis, 2001, for more detailed descriptions of symptomology):

- use of the Internet to facilitate change in negative mood states
- distorted or maladaptive perception of social benefits online, for example the feeling that the Internet is their only source of friendship
- compulsive Internet use; lack of self-control associated with feelings of guilt, which may result in lying or secretiveness
- excessive amounts of time spent online
- withdrawal symptoms when away from the Internet; cravings and excessive preoccupation
- perception of greater social control when interacting with others online compared to face-to-face situations, associated perhaps with "black and white" thinking, for example "people treat me badly offline."
- negative personal, social or occupational outcomes associated with Internet use, for example failure to meet personal or role obligations, neglect of previous sociable or leisure activities, social isolation, financial problems

From a use and gratifications perspective, there are trends in terms of personality, type of Internet use and PIU. Several studies indicate that those individuals who report negative outcomes associated with their use of the Internet seem to be drawn to its interpersonal functions (Caplan, 2002; 2003; Morahan-Martin & Schumacher, 2000; 2003; Young, 1997). In terms of personal traits, studies have identified associations between PIU and loneliness, social disinhibition (Morahan-Martin & Schumacher, 2000), and shyness (Yuen & Lavin, 2004).

Based on his own empirical investigations as well as a cognitive model proposed by Davis (2001), Caplan presented a theory of problematic Internet use and psychosocial well-being (Caplan, 2002; 2003) which posited that people who have deficiencies of social interaction, for example shyness or loneliness, see themselves negatively in terms of interpersonal skills and are more likely to develop a preference for CMC, perceiving it to be less threatening and more satisfactory than face-to-face interactions, indeed quite possibly liberating. As already discussed there is empirical evidence to suggest that this may be the case (see "Personal differences in Internet use and motives"). As a result of the

outcome of the online interaction, the individual may become more or less likely to repeat the activity due to operant conditioning. A positive outcome will lead to positive reinforcement which will reinforce repetition. With repetition of the online activity over time, maladaptive cognitive distortions about CMC may emerge in the thinking of some individuals, in relation to themselves and the world in general (Davis, 2001). They may ruminate on their problematical Internet use, rather than focussing on other aspects of their lives, and in such a way that they do not take action to solve the problems they face. Rumination will also bring into mind the Internet and associated experiences serving to reinforce its use further. They may develop negative thoughts about themselves, polarised views about their social incompetence offline compared to the situation online, again encouraging further online interaction. Such cognitive distortions are triggered each time any Internet-related stimulus is encountered.

From the discussion it seems that problematic Internet use is recognised as a potentially negative effect of online activity particularly for people who are socially isolated, anxious or under-confident. However, there are no reliable data to indicate how prevalent this problem is, leading many scholars to speculate that it is a very small problem, and that for particularly vulnerable people the potentially liberating, empowering and therapeutic aspects of CMC should not be ignored (Davis, 2001; Griffiths, 1998b; Thurlow et al., 2004). After all, as Davis (2001) points out, the Internet is now a daily reality, one which when used healthily is a helpful tool, albeit one which does consume time (Thurlow et al., 2004, p157). Davis sees Internet use as a continuum with healthy use on one side and pathological use on the other. Problematic use of the Internet is less of a product of the technology itself; rather it is the individual who determines where his/her behaviour lies on the adaptive-maladaptive continuum.

Social support

The growth of online support groups

Extensive research has established a link between social support and health and well-being (for overviews see Cohen, 2004; Cohen & Wills, 1985). Social support may be obtained from a variety of sources including, friends, family, co-workers, even strangers. The benefit of seeking support from a more formalised forum such as a self-help or support group is the interaction with peers who offer a perspective which differs from that of social, family or professional contacts. There is the opportunity to access a wider range of views,

based on personal experience, with perhaps more time than would be available from a professional, friend or family member. Generally speaking these groups are "based on principles of empowerment, inclusion, non-hierarchical decision making, shared responsibility, and a holistic approach to people's cultural, social and economic needs" (Braithwaite et al., 1999, p125). Membership of such groups may foster independence and a sense of autonomy for participants, and yet may also create collective solidarity (Burrows et al., 2000)

The rapid growth of Internet access has brought with it the emergence of computer-mediated social support (CMSS). The constant and global coverage of the Internet enables people to contact a supportive peer group which may otherwise be difficult or impossible. CMSS usually takes the form of a bulletin board, listserv or chat room whereby members may actively communicate with each other around a specific issue, with some being more passive in their involvement, simply reading posts submitted by others. There has been a huge proliferation of online social support groups, covering a diverse range of health and personal welfare issues (for an extensive list see http://www.cix.co.uk/~net-services/care/list.htm). Research has suggested that groups concerned with health conditions which are stigmatising, embarrassing or disfiguring in their effects as well as those which are not well understood and somewhat neglected by the medical community, are more evident online, for example chronic fatigue syndrome, AIDS, alcoholism and depression (Davison et al., 2000).

Just as communities are no longer focussed around neighbourhoods, but on social networks, the Internet has facilitated the networking of social support, thereby meeting needs which at one time were met more easily on a local basis (King & Moreggi, 1998). However Pleace et al (2001) do not attribute the emergence of CMSS to technological determinism, but rather the exploitation of the capacity of the Internet for interpersonal and mass communication in a social context of increasing self-reliance and reflexivity, one in which the authority of orthodoxy and tradition is increasingly questioned. Pleace et al (2000) speculate that faced with a diminishing welfare state, "individuals with the capacity to do so are making their own arrangements when the welfare state cannot help them quickly enough or cannot deliver what they need."

There is much debate as to whether CMSS groups constitute real communities, providing true support, and what the implications of their existence are for health and wellbeing, as I shall now discuss.

Can social support occur online?

Extensive qualitative research into the phenomenon of CMSS has been carried out by Burrows and colleagues (see Burrows et al., 2000). Using a standard categorisation of social support (Cohen & Wills, 1985) they analysed random samples of exchanges from virtual self-help groups dealing with diabetes (Loader et al., 2002) and depression (Muncer et al., 2000). They also participated in and analysed a chat room for problem drinkers (Pleace et al., 2000). They concluded that online groups can offer people esteem support, informational support and social companionship, to varying degrees depending on the level of active participation or the focus of topic of the group. The diabetes group, for example, was more concerned with informational support, whereas there was more social companionship and esteem related posting in the depression group (Muncer et al., 2000). Their findings were reinforced by data from users and co-ordinators of CMSS collected by semi-structured interviews.

Analysis of the postings of other groups (concerned with a range of issues, for example disability, breast cancer, motherhood, single motherhood, Huntington's Disease, siblings of children with chronic health conditions) also indicate that the social support and therapeutic processes of offline support and self-help groups are apparent in CMSS groups, with emotional and informational support being most evident (Braithwaite et al., 1999; Coulson et al., 2007; Drentea & Moren-Cross, 2005; Dunham et al., 1998; Sharf, 1997; Tichon & Shapiro, 2003). Other supportive processes evident in online support groups include emotional expression, empathy, modelling (by relating personal experiences), self-disclosure, acceptance, expression of willingness to listen, mutual problem solving and catharsis (Finn, 1999; Mesec & Mesec, 2004; Salem et al., 1997; Winefield, 2006). There are also reports of dimensions of online support which are less evident in offline situations, for example Braithwaite et al (1999) in their study found members occasionally contributed less conventional forms of self-expression such as poetry. The authors point out that the textual nature of CMSS, as well as the anonymity and reduced time pressure may create a more conducive situation for the creation of poetry. Humour was also evident in the postings of the group, as well as the forum studied by Tichon and Shapiro (2003), and it was speculated that anonymity online makes the use of humour in a support forum less risky. Drentea and Moren-Cross (2005) identified communication which served to build, protect and maintain the sense of community and hence support in their study of an

Internet group for mothers. It could be that this is more necessary online than in face-to-face groups due to the time taken to adapt to CMC, as well as the lack of nonverbal communication and the potential for misunderstandings to occur.

Evidence therefore indicates that the interpersonal processes which characterise social support seem to be occurring via CMC. However the therapeutic value of CMSS is as yet to be established. A systematic review of the effects of health-related virtual support groups, carried out by Eysenbach et al (2004) concluded that although qualitative studies had provided descriptive data regarding self-help processes and perceptions of CMSS there was no robust evidence to establish its efficacy in terms of health and social outcomes. Research evidence as it exists is limited by the incorporation of CMSS into complex, mixed intervention packages. There are only a small number of studies evaluating "pure" CMSS, none of which are randomised controlled trials. Most studies did not show an effect on outcome measures, nor did they indicate any harmful effects. The reviewers highlight the need for randomised controlled trials with factorial design or evaluations of pure peer-to-peer interventions, to establish the effects of CMSS. Methodological challenges are faced establishing a measurable definition of social support (Pleace et al, 2001), defining and obtaining a representative sample, studying "natural" self-help processes in a controlled research environment, and lack of "compliance" by participants (Eysenbach et al., 2004). Caplan and Turner (2007) contend that research into computer-mediated social support has been limited by a lack of detailed and empirically testable theories. In the next section I describe a model of computer-mediated comforting communication, which they formulated to address this need, as well as other theories of CMC which have been applied to CMSS.

Theories of computer-mediated social support

Based on an *appraisal theory of comforting communication*, Caplan and Turner (2007) have proposed a framework to explain the process of online emotional support, which may provide the foundation for developing and testing hypotheses pertaining to the effectiveness of CMSS groups. The theory proposes three conditions necessary for effective *comforting* (a specific aspect of social support, dealing with emotional distress), which Caplan and Turner argue can be met by the unique features of CMC. Firstly, as has already been discussed, for some people, particularly those who are less socially secure, it may engender feelings of comfort, safety and willingness to discuss upsetting

matters. Anonymity and reduced social cues are the features of CMC which may facilitate self-disclosure and would be particularly valuable to people who feel stigmatised or sensitive about their personal difficulties.

The second condition for effective comforting is that talk must focus on the distressed individual's thoughts and feelings about the upsetting issue. Online there may be more possibilities for individuals to find others with whom they find personal discussion comfortable, people who have had similar experiences, in similar circumstances, whose online communication may convey empathy and facilitate discussion of sensitive issues. Preece (1999) found that empathy was a very prominent feature of an online medical support group, and attributed this to the high density of people with common experiences or issues. Research by Tidwell and Walther (2002) indicated that people meeting for the first time via CMC produced more direct, disclosive and intimate exchanges than those in a face-to-face situation, suggesting that it is easier online to focus on personal thoughts and feelings.

The final way in which CMC may be conducive to comforting communication is by facilitating adaptive reappraisals of the subject of distress by means of writing personal narratives. The act of verbal disclosure via CMC may serve to organise thoughts and feelings in such a way that they have structure and meaning, and feel more manageable. Such clarity brings the possibility of a re-evaluation of the situation with the effect of alleviating distress. Personal narratives were found to be almost as evident as empathy in Preece's analysis of messages to the support group which was the subject of her study (Preece, 1999).

Other scholars draw on *weak tie network theory* in their contributions to theoretical discussions of CMSS (see Robinson & Turner, 2003; Wright & Bell, 2003). Weak tie relationships are those which are separate to the pressure and dynamics of close family and friendships. Weak ties may be more supportive in ways which close ties can not, due to their objectivity and more detached connection. Walther and Boyd (2002) suggest that the Internet expands the potential to form supportive weak ties due to its diverse and prolific coverage, coupled with the organisation of groups around specific topics. King and Moreggi (1998, p81) also point out that the social norms of virtual communities are such that they "allow for, and even encourage contact with relative strangers." There may also be more potential to draw on a wider range of perspectives compared to the smaller strong tie groups of close personal relationships. Communicating via CMC with someone you do not know offline, in

conditions of perceived anonymity and privacy, may also serve to ease the disclosure of stigmatising or embarrassing information, and eliminate or lessen any perceived burden on close relationships.

Walther et al (2005) propose that hyperpersonal and SIDE perspectives of CMC have implications for CMSS groups. Although individuals may participate in a group with little knowledge about each other apart from their issues of common concern, it is that commonality which will engender a sense of connection and the shift towards a social identity which may be conducive to a supportive relationship, particularly for people who feel socially isolated or stigmatised (Bargh and McKenna, 2004).

Walther et al (2005) also argue that hyperpersonal interaction may account for the close relationships which are apparent in some online support groups.

I shall now discuss descriptive data from qualitative studies which have provided insights into the perceptions, motivations and experiences of people who take part in online support forums, which may contribute to theoretical frameworks.

Perceptions of computer-mediated social support

Interviews with participants in CMSS groups have indicated the dimensions of CMC which attract people to its use as a medium for social support, the themes of which I shall now summarise (for details of individual studies see Colvin et al., 2004; Shaw et al., 2000; Walther & Boyd, 2002).

The reduction of social distance via the Internet was seen as a way to expand resources for social support beyond that which was available in local or personal networks, to include a larger and more diverse group of people, with whom there was common ground and more potential for understanding and empathy, as well as advice and information based on experience. Seeking social support in this way also lessened the burden on one's personal network, and met the need to make social comparisons in order to achieve a sense of normalcy and accuracy in one's world at times of uncertainty (see Davison et al, 2000). However at the same time as reducing social distance, the Internet may also maintain it, such that people were less concerned about stigma or dependency.

Anonymity was also a major attraction of CMSS, alleviating embarrassment, reducing fears of judgement, reducing self-consciousness in relation to personal appearance and making it easier to open up about sensitive issues. It was also associated with a sense of egalitarianism due to the lack of social context cues.

Anonymity also enables people to lurk, and therefore obtain support vicariously without the need to contribute themselves.

The ways in which one's interactions can be managed online are perceived to be conducive to CMSS. With less pressure for an immediate response and time to read and construct messages carefully and at one's convenience, people reported a sense in which self-expression was enhanced. People also felt they had more choice over their level of involvement in online groups, being able to engage and disengage more easily than in face-to-face situations, thereby accommodating their needs in terms of time, topic or social confidence.

The final aspect of CMSS which was viewed as beneficial was its accessibility, compared to face-to-face support. There is flexibility in terms of time and location, making it more accessible at participants' convenience or in times of crisis, and overcoming barriers of geography, health or mobility limitations. Data from a study of an online support group for breast cancer found that 40% of all use occurred during out of office hours, between 9pm and 7am (Gustafson et al., 1993) implying the utility of a more constantly available source of support.

Some of the aspects of CMC which were perceived as advantageous to social support, were also raised as potentially problematic by some individuals. Its difference in timing, whilst affording more control over interactions, could also be frustrating due to lack of immediacy of responses. Similarly the drawbacks of social distance were that it limited the potential for contact of a more personal nature or the provision of tangible forms of support, whilst the anonymity of CMC prompted some participants to miss social context cues and physically comforting forms of expression. For some there were also concerns about judging authenticity and sincerity online. A potential drawback in terms of accessibility was the large amount of messages one may receive, with implications for time commitments.

Overall research indicates that the benefits of CMSS outweigh the drawbacks, although as King and Moreggi (1998) point out evidence is largely based on self-selected samples which cannot be assumed representative. However for those who do engage regularly in online support groups, CMC seems to not only be a convenient way of contacting pre-existing sources of support, but also a way in which a unique, personalised and potentially beneficial form of support is enacted, one based on contact with relative strangers which extends and complements the support available in personal or local networks. It may be particularly useful for those who are unable to find support locally due to lack of

services or the rarity of their particular issue, as well as those who are limited by disability or a reluctance to access support from their personal or local resources due to issues of stigma. Research has also suggested that men may also be more likely to use online support rather than face-to-face (see Salem et al., 1997; White & Dorman, 2001). Burrows et al (2000) comment on the irony that "although rapid technological change is often conceptualised as one of the major forces invoking feelings of both stress and isolation it is also, paradoxically, held up by some as the means by which new forms of social connection and support will emerge." Burrows' observation highlights the polarised views of the Internet as either a dystopia, bringing social isolation, neighbourhood breakdown, disinhibited behaviour, and loss of individualism and creativity, or alternatively "a utopia, liberating people to form a global egalitarian community" (Katz & Rice, 2002, see Thurlow et al., 2004, p54). As has been discussed the relationship between the Internet and interpersonal dynamics, relationships and wellbeing is a complex one, which, as Katz and Rice suggest, is one of synergy. It may extend and enhance aspects of social life, but "like any form of communication it is as helpful or as harmful as those who use it" (see Thurlow et al., 2004, p54).

This chapter will finish by considering how CMC may impact on two specific aspects of society; the provision of online counselling and the well-being of people with disabilities.

Internet-based counselling

The Internet is a fast and relatively cheap form of communication which is becoming increasingly available to western populations. These qualities as well as its potential for interpersonal communication unlimited by geographical barriers have probably contributed to the emergence of Internet-based counselling as a small but growing trend in psychological services.

As a result of the cross fertilisation between the fields of Internet communication and psychological counselling, a range of online interventions is feasible according to conceptual approach, intervention procedure and communication mode. Clients may access stand alone therapeutic self-help style programmes, with or without human support, via websites, or use blogs as an ongoing record of their personal experiences, for therapeutic analysis. However the focus of this section will be the provision of more interactive forms of therapy, that is, the one-to-one counselling which may occur in real time via

chat or webcam, or asynchronously via email, as well as group therapy provided in forums or chat rooms.

It is apparent from the literature that opinions on the utility of online counselling vary considerably. Abney and Maddux (2004) attribute the controversy concerning the use of computers and the Internet in counselling to differences in the underlying assumptions associated with cognitive psychology as opposed to behavioural psychology. From a cognitive psychological perspective, man is a dynamic choice maker in contrast to the mechanistic model on which behavioural psychology is based. Abney and Maddux explore these differences further, characterising them as modernist and postmodernist perspectives and concluding that "tolerance of dual approaches to applying technology in counselling will best permit the counselling field to progress."

At this early stage of its existence there is relatively little research evidence to answer the questions raised by current debate. Researchers face the challenges of evaluating the counselling process in a unique and complex environment as well as difficulties obtaining sufficient numbers of participants. I shall review the potential benefits, strengths, limitations and challenges which have been raised in discussions around practical and ethical aspects of Internet-based counselling in its various forms, as well as therapeutic process and outcomes (Abney & Maddux, 2004; Barnett, 2005; Carlbring & Andersson, 2006; Fenichel et al., 2002; Griffiths, 2001; Mallen & Vogel, 2005; Mallen et al., 2005; Rochlen et al., 2004; Schultze, 2006) and relate these to empirical research where appropriate.

The practical aspects of Internet-based counselling: issues of convenience, cost, accessibility and technology

The Internet has the potential for 24 hour access from a wide variety of locations other than the therapist's office. It can therefore diminish constraints of time, space and travel from the perspective of counsellor and client. For those with easy access to the technology this can reduce costs and allow more flexible scheduling, of particular relevance to those clients with restrictions on their time, especially those who are not available during office hours, for whom email mediated therapy may be a more accessible option. Griffiths (2001) however raises a potential risk of such convenient access to counselling services, suggesting that people may use the online therapist as a crutch, and neglect to use their own coping resources.

The global coverage of the Internet breaks down obstacles to face-to-face therapy, opening up more opportunities for people who have difficulty accessing conventional services for reasons such as physical or sensory disability, agoraphobia, or being resident in remote locations or areas with limited local services. Other groups of people may benefit from the nature of CMC, particularly in its textual form, for example those with speech and/or hearing difficulties as well as those who feel embarrassed, nervous, anxious or stigmatised about the person-to-person counselling situation.

The online therapist can also make use of the seemingly limitless resources available on the Internet as a means of providing clients with various forms of supplementary material quickly and easily via hypertextual links to websites, video clips, documents, online support groups, assessment tools and interactive programmes, opening up more options than would be possible in the consulting room.

Having raised the Internet as a potentially convenient way of accessing counselling services, it should be emphasised that this is not an option available to all. Although rapidly expanding, computer ownership and Internet access is not a universal phenomenon, even in western society. There is a cultural bias inherent in computer and Internet access away from lower income, less educated, older populations (see previous section "The digital divide"). As Mallen et al (2005) point out, those underserved populations who have the greatest need for services are likely to be those with less access to such technologies, such that they continue to be subject to exclusion. Barnett (2005) advocates the need to broaden access to online-counselling services to include those typically disenfranchised.

In addition to low income level, deficiency of skills may also rule out online counselling as an option for some people. At least a certain level of literacy, typing, computer and CMC expertise is necessary to access this type of service, and for text-based counselling it is argued that in addition to basic skills a certain affinity and confidence for self-expression through writing is required in order for a therapeutic relationship to develop.

Whilst highlighting the speed and flexibility afforded by the Internet in the context of counselling, the technology of course is not immune to problems. Interference by hackers, software incompatibility, hardware defects, viruses and time lags, can threaten security and disrupt communication, with the potential to cause distress to clients. I shall now consider the ethical implications of this, and other aspects of online counselling.

The ethics of Internet-based counselling

The Internet can enable counsellor and client to enter a therapeutic relationship without being in the physical presence of each other, indeed they may be a great geographical distance apart and may never have met each other. Whilst opening up new possibilities for the field of counselling this brings ethical problems. Probably the most critical challenge is detection and intervention in the case of crisis, for example threatened harm to self or others. Addressing this issue, Mallen et al (2005) recommend the arrangement of an emergency plan agreed with the client before therapy commences as part of the process of informed consent. This would include details of the client's identity, address, telephone number, physician, emergency contacts and local emergency services as well as the procedure which would be followed in the event of a crisis.

Some authors (for example Carlbring & Andersson, 2006; Mallen & Vogel, 2005; Mallen et al., 2005) would argue that emergency intervention is impossible online, therefore face-to-face assessments should be made prior to treatment so that clients at risk of crisis are provided with an alternative regime. Although being geographically distant from the client may compromise the therapist's role in crisis intervention, and the asynchronicity of email in particular may be less than satisfactory in such a scenario, Fenichel et al (2002) argue that it is no more difficult to locate a client in the online situation than it is in telephone hotline clinical work. They suggest that rather than being disadvantageous, the invisibility and textual nature of online communication encourage the depth of self-expression which can be supportive at times of crisis, citing the SAHAR service in Israel as an effective and accessible example of online crisis management (Barak, 2007). Conversely, this tendency toward depth of expression and the potential for instant intimacy have been raised as possible risks of the online therapy situation, possibly increasing the risk of dependency.

As well as an emergency procedure, pre-counselling information should also prepare clients for the possibility of technical failure and equip them with strategies to cope in such an instance. Recently developed guidelines make such a recommendation (see Chester & Glass, 2006). However, one third of online counsellors (n=67) surveyed by Chester and Glass (2006) made no such provision.

In the same survey another lack of ethical awareness was evident. Only half of the sample was using any form of encryption software to protect the confidentiality of the therapeutic interaction and client records. Client

confidentiality was raised by another sample of over 2000 US mental health professionals (Wells et al., 2007) as being a great concern in regard to online treatment, and use of encryption software has been identified as a recommended standard of practice (see Chester & Glass, 2006). It is clear that there is a need to establish regulation of online counselling services as well as standards of training for practitioners.

The issue of verifying identities (both client and counsellor) online raises practical and ethical challenges, which may once again be addressed by a preliminary face-to-face meeting in the context of a regulated professional service.

The ability of the Internet to transcend state and international boundaries prompts ethical and legal questions relating to licensure and legal responsibility in the event of crisis or dispute (Chester & Glass, 2006; Griffiths, 2001; Mallen et al., 2005; Rochlen et al., 2004; Wells et al., 2007). Barnett (2005) urges the resolution of these jurisdictional issues so that the field of online therapy can develop.

The online therapeutic process

Many commentators (for example Alleman, 2002) have highlighted the issue of loss of nonverbal cues in the text-based CMC situation and how this may affect the relationship between counsellor and client, which is regarded as central to the therapeutic process. They raise questions as to whether rapport is more difficult to establish, client emotional responses more difficult to detect and whether misunderstandings are more likely to occur.

As discussed earlier, there is evidence that in some instances close and intimate relationships can occur online. Indeed it has been proposed that the concept of online disinhibition, may benefit an online counselling relationship (Fenichel et al., 2002; Griffiths, 2001; Rochlen et al., 2004). The visual and psychological anonymity of text-based communication online is conducive to behaviour characterised by an apparent reduction in concern for self-presentation and the judgement of others (Joinson, 1998). From a therapeutic perspective this may enhance self-expression and reflection and may also ease self-disclosure, particularly of personal or potentially stigmatising information, such that dignity and self-assurance are preserved (Schultze, 2006). Indeed Fenichel et al (2002, p486) argue that "Freud's psychoanalytic technique was designed to foster the very disinhibition that naturally occurs so easily on the Internet." With fewer, if any, social masks to remove, clients may bypass the formality, reservation and

insecurity of the first stages of the counselling process, thereby engaging in a high degree of intimacy, honesty, and discussion of core issues earlier perhaps than would occur in face-to-face therapy (Rochlen et al., 2004; Schultze, 2006). Some supporters of online therapy would go further and argue that without the distracting, superficial and possibly distorting aspects of face-to-face interaction, a more direct connection between psyches is possible (Rochlen et al., 2004), perhaps to the extent that the boundaries between self and other become blurred creating a feeling of overlap (Suler, 2004).

Some proponents of online therapy recognise the drawbacks of a lack of nonverbal communication and emphasise the need for counsellors to develop their online therapeutic communication skills, by learning alternative ways of expressing empathy and other paralinguistic features, as well as practicing how to be more explicit in their expressive language and how to monitor client reactions by checking back as sessions progress (Mallen et al., 2005).

Mallen et al (2005) argue that whilst text-based forms of online therapy are feasible, face-to-face skills remain at the heart of service delivery and suggest that videoconferencing would be the most desirable medium for Internet-based counselling. In their experimental research, counsellors conducted single sessions via synchronous chat with a confederate posing as a college student presenting with a standardised problem (Mallen & Vogel, 2002). Although practitioners accurately assessed the presenting problems and were generally satisfied with the process, analysis of the session transcripts indicated that, compared to face-to-face sessions, counsellors offered less approval, reassurance, and interpretations, and posed fewer challenges and questions of the client.

Other studies of process variables in online counselling demonstrate mixed results. In a study comparing videoconferencing with face-to-face counselling for families with epileptic teens, client ratings of therapeutic alliance in the video condition were significantly lower than in the face-to-face condition (Hufford et al., 1999).

However, in a qualitative case-study of counselling via videoconferencing technology by Lewis et al (2004), clients reported feelings of empowerment, unexpected depth of emotion, and immersion in the counselling process.

Furthermore participants in a study by Cook and Doyle (2002) provided ratings of therapeutic bonds and tasks experienced during textual Internet counselling (synchronous or asynchronous) comparable to normative face-to-face

counselling data. Ratings of therapeutic goals were superior in the online condition. This study is limited however by the small number of self-selected participants (n=15) and the lack of an adequate comparison group.

In a comparative experimental study of synchronous chat and face-to-face semi-structured counselling (Cohen & Kerr, 1998), client ratings of therapist attractiveness, expertise, and trustworthiness did not differ between the two conditions. Evaluations of the sessions did not differ significantly in terms of depth, smoothness and positivity between the two groups of subjects, although a higher level of arousal was reported in the face-to-face condition. Once again these findings are limited in terms of their generalisability due to the low number of participants (n=24) who were all undergraduate students.

In contrast to the "gold standard" view of face-to-face therapy, Schultze (2006) values the unique and beneficial aspects of the psychological anonymity of text-based forms of online therapy and therefore would resist their replacement by simulated real-life encounters as technology advances. Internet-based counselling, in particular text-based forms, should perhaps be seen as a different entity, rather than a transplantation of face-to-face therapy to overcome distance; an alternative regime rather than aspiring for equivalence to person-to-person counselling. It may suit certain clients, counsellors and conceptual approaches more than others. Alleman (2002) argue that some highly experiential approaches rely so heavily on real-time nonverbal communication that they could not be adapted for any communication medium other than face-to-face interaction. The high degree of structure characteristic of cognitive behaviour therapy has been proposed as being particularly suitable for online therapy (Mallen et al., 2005; Rochlen et al., 2004), and indeed seems to be the approach most widely available via the Internet (Chester & Glass, 2006).

Barak and Bloch (2006) analysed the transcripts from online chat sessions offering support to highly distressed individuals to determine which factors related to helpfulness as perceived by clients and counsellors. Consistent with research into face-to-face counselling, deep, smooth conversations which yield positive responses and arouse clients' emotions are seen as more beneficial than shallow, disjointed conversations which leave clients emotionally indifferent. The length of text, from both client and counsellor, was also a relevant factor.

With respect to text-based CMC, the lack of visual cues to gender, age, ethnicity and social status may have an equalising and advantageous effect on

client-counsellor interaction (Chester & Glass, 2006). However Mallen and Vogel (2002) argued that without the presence of nonverbal cues, the use of stereotypes as a means of compensation may be more likely. Trainee therapists were found to differ in their approach to male and female clients, during an experiment in which they engaged in a synchronous online session with someone acting as a client. Each trainee interacted with the same confederate presenting the same issues, the only difference being whether the client was said to be male or female. There were differences in trainees' responses depending on the apparent gender of the client. Counsellors reported being significantly more satisfied with the female client, whereas the male client was assessed as more hostile and proud. Mallen et al (2005), also question whether clients may feel less understood because the cultural context is harder to comprehend online. The potential for counselling to occur across international and cultural boundaries via the Internet highlights further such a possibility.

Lago (1996) also raises the issue of stereotyping or idealisation by the client in the absence of a physically present therapist, warning of the possibility of fantasy development such that expectations of the therapist become exaggerated and unrealistic.

In addition to invisibility, online clients may benefit from the privacy and familiarity of their physical location, creating a feeling of subjective protectedness, which Schultze (2006) regards as advantageous over face-to-face counselling. According to Schultze, this feeling of safety is enhanced by the permanent possibility of withdrawal due to the availability of an undo option, something which is not so easily achieved in more direct forms of personal contact.

Rochlen et al (2004) argue that the nature of textual CMC lends itself to joint ownership of therapeutic dialogue and as such the power differential between counsellor and client is diminished to the benefit of the interaction. Both parties have time, a permanent record and editing tools which facilitate reflection and planning, such that they may pay close attention to their own process whilst remaining engaged in dialogue. This may also lead to a deeper understanding for both parties and an enhanced sense of control for the client, important components in therapy (Mallen & Vogel, 2005). Murphy and Mitchell (1998) argue that the very process of writing an email, thereby translating psychological events into words, is in itself therapeutic, enabling clients to externalise and objectify their problems, gaining some clarity from which to proceed. The slower pace of text-based online therapy also provides respite

time for both counsellor and client during the emotionally charged and challenging process of therapy (Schultze, 2006). Conversely time delays may disrupt the counselling process, causing distress to clients.

The outcomes of online therapy

Studies of the outcomes of online counselling generally report positive results in terms of client improvement. However, the impact of this research is limited due to a tendency toward evaluation of a restricted number of short term outcomes (mainly symptom relief, without due consideration of, for example, client satisfaction or insight) and the use of small samples drawn from a limited pool, mainly university staff or students. The research as it exists therefore provides preliminary evidence of the usefulness of online counselling, but further investigations are needed to address these limitations and extend the knowledge base.

In a study by Robinson and Serfaty (2001), 23 women recruited from the staff and students of a large British university college who appeared to fulfil the diagnostic criteria for bulimia nervosa, were offered email-based therapy by two experienced specialist counsellors. Results from 19 participants who completed outcome measures at 3 month follow-up, showed significant reductions in symptoms of the disorder. Word count, as a measure of engagement with therapy, was found to correlate with outcomes.

Lange et al (2001) carried out a controlled trial of online therapy for posttraumatic stress and grief, based largely on writing tasks, administered to students who participated in return for course credits. There was a significant improvement in trauma-related symptoms and general psychopathology for the experimental group (n=13) compared to the waiting-list control group (n=12).

Goal-orientated cognitive behaviour therapy via synchronous chat for people with chronic disabilities was found to be potentially useful in reducing loneliness compared to a waiting list control condition (Hopps et al., 2003). This effect was maintained 4 months post-treatment. The study however involved only 19 subjects in total, who were possibly more able, educated and independent than the wider disabled population.

Cohen and Kerr (1998) conducted a randomised trial comparing semi-structured face-to-face counselling with a similarly formatted intervention delivered by synchronous chat to students (n=24). Significant and comparable reductions in anxiety were evident in participants of both conditions after one session. However, as well as the low number of participants, this study is also

limited in that individuals presenting with more severe issues were excluded from the sample.

Not all studies have generated positive results. A randomised control trial, involving 52 subjects, conducted by Meier (2000) found no difference in outcome measures of occupational stress, psychological strain or coping strategies between waiting list controls and participants in a facilitated online synchronous chat support group for the discussion of work-related stress by practicing social workers, despite expressions of satisfaction by members of the treatment group.

A qualitative approach to evaluation of online counselling was adopted by Jedlicka and Jennings (2001) in their study of marital therapy conducted via email. They concluded that their experiences of providing services in this way constituted marital therapy. Moreover they argued that email in itself may be therapeutic, or as they put it, *ecathartic*, diverting aggression and reducing tension between the couple. The medium may also reduce anxiety and its interference with the therapeutic process. The counsellor also gains emotional distance and time for reflection which may facilitate the provision of effective well thought out therapy. Jedlicka and Jennings (2001, p13) also concluded "that email therapy can facilitate transition to conventional, office-based, therapy when the latter modality is more suited to clients' needs." Similarly, Grunwald and Wesemann (2007) studied an information and online-consulting service for people with eating disorders and their associates, and suggest that the provision of an Internet-based service is less inhibiting as a first point of contact, from which the possibility of further more conventional forms of input may be suggested. Such schemes may offer a way in to counselling for some people, with the potential to improve the care they receive from the health care system.

The future of online counselling

As Fenichel et al (2002) point out, the phenomenon of online counselling shatters three of the basic premises of therapeutic interaction, namely that it should be based on face-to-face contact, talking and real-time interaction. Online counselling is therefore different in essence, and caution is needed when applying the principles of more traditional forms of therapy in its evaluation. Rather than a substitute for face-to-face counselling, or therapy across distances, it should perhaps be seen as an alternative, adjunct or gateway to other forms of intervention.

Much has been written hypothesising the benefits and drawbacks of this form of intervention and its suitability to different therapeutic approaches or groups of people, depending on their personal, demographic or clinical characteristics. There are those, for example Mallen et al (2005), who would argue against its utility for people with severe mental health issues. Although preliminary research findings into process and outcomes indicate that the Internet may be a valid medium in which to provide counselling, more research is needed to answer the many questions raised by debate in the literature.

As well as building on previous studies and carrying out trials involving larger samples and measuring longer term outcomes, there is a need to establish which client groups and therapeutic approaches are effectively served by online-based services. In particular, investigations should aim to ascertain its efficacy for those individuals who for various reasons underutilise face-to-face counselling and for whom online counselling has been proposed as an alternative option. Research investigating the issue of crisis intervention is also needed, as well as studies comparing different forms of online therapy (email, chat or video-based).

In addition to further research there is also a need to address the ethical and legal concerns relating to online counselling, through the establishment of standards and regulations for practice and training, as well as the development of initiatives to broaden its availability, given that those people who underutilise face-to-face services may well also be disadvantaged in their access to Internet-based services.

CMC and disability

In this section I shall explore the impact of Internet-based communication on the lives of people with disabilities. Drawing on a social model of disability (Guo et al., 2005; Oliver, 1990; 1996), as well as empirical research, I shall examine the potential of online communication to affect quality of life for people with disabilities and also the barriers which contribute to the disability divide in terms of digital inclusion. I shall finish this section by focussing on the use of information technology, particularly the Internet, by people with autistic spectrum disorders, thereby setting the scene for this piece of research.

The social model of disability

The social model of disability recognises that whilst some people may have physical, cognitive or psychological profiles which differ from the statistical

norm, ultimately their disability is attributable to barriers existent in the social environment, rather than individual difference or impairment. As a result of societal bias toward normative expectations of physical and mental functioning, there are deep-rooted physical and attitudinal barriers which restrict opportunities for social participation by people with impairments. Disability has diverse implications for behavioural, economic and social aspects of an individual's life, and brings risks of disenfranchisement and isolation (Braithwaite, 1996). People with disabilities are therefore at risk of negative social and emotional outcomes such as depression, loneliness and alienation, as well as being disadvantaged in terms of access to social interaction, information, services, education and employment.

Guo et al (2005) propose that the Internet can alleviate physical, geographical and attitudinal barriers to social participation for disabled people. I shall now explore the serendipitous benefits (see Roulstone, 1998) of this new technology for some disabled people in breaking down such barriers, thereby potentially reducing disadvantage in key areas of life such as mobility, communication, socialisation and employment, with implications for their inclusion, wellbeing, independence, identity and empowerment.

CMC breaking down barriers to social participation

There are three main characteristics of the Internet which offer ways in which the obstacles to the social participation of people with disabilities may be reduced: the capacity to transfer data between computers at great speed and over vast distances, the provision of an alternative form of communication to those based on spoken language, and the lack of necessity for people to see or hear each other in the course of their online interactions.

The Internet can diminish physical barriers

The Internet is a medium by which people with disabilities may overcome mobility-related challenges which reduce opportunities for participation in everyday life, for example inaccessible accommodation and transport. Online they may be afforded more opportunities to communicate with others and access information in situations more suited to their own particular physical requirements.

Given the vast size and interconnectivity of the Internet there is also the potential to greatly expand the size and geographical distribution of one's social network more than would be possible via any other medium. In a survey of disabled Internet users in China (n=122) carried out by Guo et al (2005),

62.1% of respondents claimed most of their friends contacted via the Internet were distant, while only 2.5% reported most of their friends as distant before coming Internet users.

As I shall discuss later, the opportunity to extend one's social network over large distances has the potential to be of particular value to people in minority groups, such as individuals with disabilities, who are likely to be geographically isolated from a peer group.

The Internet can diminish communication barriers

The characteristic nature of online communication offers an alternative way of interacting to people who are disadvantaged due to impairments affecting communication, cognitive ability, or social interaction. Stoudt and Oullette (2004) studied an online forum for people who stutter and observed that "the Internet is a context in which fluency does not depend on the spoken word." In a small survey of hearing impaired people (n=25) investigating the potential of CMC to relieve social isolation, over half of respondents claimed that they found it easier to communicate by text compared to face-to-face situations, some saying they would prefer this form of communication in all circumstances (Bishop et al., 2000).

By means of a survey, focus groups and structured conversations the perspectives of people with acquired cognitive impairments, their carers and professionals were explored by Todis et al (2005). Several advantages of email were identified, including the greater degree of control over one's communication. In contrast to telephone communication, users of email felt under less pressure, and could take as long as they needed to read and compose messages.

Egan et al (2006) trialled the use of email interviewing with traumatic brain injury survivors, to counter impairments affecting information processing, response formulation, recall and concentration thereby enabling participation in research by this group. Participants reported an "overwhelming" preference for email interviewing compared to face-to-face situations, and several said that they felt they expressed themselves more effectively in writing than by the spoken word. Once again control over the interaction and time for reflection emerged as benefits of this mode of communication. As well as asynchronicity of online communication being valued, the textual mode was also seen as a means of reducing memory load. Respondents also reported being able to concentrate better online, and attributed this to the lack of visual distraction of

the interviewer and interview setting. They also noted a greater focus to their answers than would have occurred in a face-to-face situation, being less tangential, with time to assemble one's thoughts. The researchers observed that in many cases email interviews yielded data which was rich, conveying insight and humour, thereby challenging stereotypes associated with survivors of traumatic brain injury.

Whilst there are many ways in which the Internet may facilitate communication for people with disabilities, it is not without its drawbacks. Comments from some respondents in studies by Bishop et al (2000) and Todis et al (2005) indicated that the lack of nonverbal communication was problematical. People with acquired cognitive impairments said they had trouble reading social cues and missed hearing a human voice (Todis et al, 2005). All of the hearing impaired users of email in the study by Bishop et al (2000) felt that factual information was better conveyed by email whilst only a quarter would choose it for conversational information, and only one in ten preferred it for emotional communication. The authors discuss this finding in relation to the particular importance of visual cues such as facial expression, posture and movement to this group of people.

From the literature it seems that, with some limitations, CMC may reduce barriers of communication affecting people with disabilities, due to its textual nature and flexibility of timing. I shall now discuss how the limited and malleable representation of the body in cyberspace may have implications for mitigating the social stigma of disability.

The Internet can diminish attitudinal barriers

In the survey of disabled adults in China conducted by Guo et al (2005), 54% of respondents agreed that there was less discrimination toward disabled people on the Internet, whilst only 11% disagreed.

The emphasis on textual communication of the Internet can reduce all participants to the same level of representation raising unique possibilities for identity construction (Cromby & Standen, 1999) and reduction of discrimination on the basis of physical appearance or speaking ability (Bowker, 1999). According to Bowker (1999) "the dominant discourses surrounding the physical appearance of bodies as a basis upon which to evaluate one's identity, self-worth and self-concept, inherent in the physical world, potentially, lose their impact." Online people with disabilities are afforded more control and flexibility over self-presentation with greater potential for normalisation and equality;

they may avoid the disabling perceptions of others and be judged on their words rather than the outward signs of their disability (Bowker & Tuffin, 2007). Although it did not involve people with disabilities, experiments carried out by Epley and Kruger (2005) may cast some doubt on the potential of the Internet to counter pre-existing discrimination. Individuals, when interacting by email with someone about whom they already had formed a stereotype, were more likely to come away with that stereotype confirmed than when interacting by telephone. Findings suggested that this difference may be associated with the greater ambiguity of email, leading people to rely on stereotypes to compensate for uncertainty. It seems that the removal of barriers of attitude may be affected by the amount and timing of self-disclosure during an interaction

The theme of self-presentation was also important to people with acquired cognitive impairments who felt that the quality of face-to-face communication was affected by the negative responses of others faced with tangible signs of the impairment (Todis et al., 2005). As well as the visual anonymity of email, the extra time to process and edit messages may also serve to remove the social barriers of disability for this group.

The promise of the Internet

From the discussion so far there are various ways in which the Internet has been proposed as a means of liberation for people with various types of disabilities from the restrictions they face in everyday life. Indeed there is evidence to suggest that this is a perception held by members of the disabled community who use the Internet. Although other forms of written communication can offer some of the potential benefits of the Internet, they are slower and less convenient.

The American National Organization on Disability (2001) claim that the Internet has had a much more dramatic effect on quality of life for those people with disabilities who are online, compared to their non-disabled counterparts. According to their survey, 42% of Americans with disabilities who use the Internet say it has significantly enhanced their ability to reach out to others with similar interests and/or experiences, compared to 30% of non-disabled Americans. Similarly, 52% of disabled Americans who use the Internet say it has helped them be better informed about the world around them, in contrast to 39% of non-disabled online Americans. In the UK a survey commissioned by the Leonard Cheshire Foundation found that 54% of disabled people considered

the Internet essential compared to 6% of the general population (Knight et al., 2002). This perception may be reflected in the survey results obtained from 136 disabled people who used the Internet, which indicated that they were more frequent users of the Internet than users from the general population, 76% of men and 62% of women using it more than once a week, compared to 58% of men and 48% of women in a National Statistics survey (see Pilling et al., 2004).

Richie and Blanck (2003) identify the extensive range of resources available via the Internet which can enhance independent living opportunities for people with disabilities. Without having to leave home there is the potential to access a wealth of information, take part in an online community, communicate with friends and family, access education and training through distance learning programmes, engage in certain types of paid employment or business, receive counselling, or shop online for an ever expanding range of goods and services. Virtual world platforms such as Second Life may enable people to build, create and move around in their own online worlds, where they may interact, socialise, and fulfil their dreams regardless of age and physical or mental health, with the potential for real life gain in terms of wellbeing, education and business (Pajtas, 2007).

This is the promise, as yet to be fully realised, of the Internet for people with disabilities. As I have already mentioned, and shall explore in more depth later, people with disabilities as a group are disadvantaged in terms of digital inclusion.

If the Internet can break down physical, communication and attitudinal barriers for people with disabilities, there are implications for their social participation and identity construction as will be discussed in the following sections.

The Internet and opportunities for social interaction

The expansive communication capabilities of the Internet, as well as its potential to reduce physical and communication barriers and suppress discrimination, can increase opportunities for social interaction for people with disabilities (Guo et al., 2005). Hence individuals may increase their level of contact with friends and family and extend their social circle via social networking sites or online forums, with the potential to affect quality of life in terms of friendships, social participation and social support.

Various studies have explored the potential of the Internet to affect the social relationships and participation of people with disabilities. In their study Guo et

al (2005) compared social interaction before and after Internet use and discovered significant increases in number of friendships and participation in public affairs and group activities, as well as overall satisfaction with social relationships and friendships. More intensive use of the Internet was associated with greater social interaction benefits for people with disabilities than less intensive use. However their results suggested that although the Internet was important to people who regularly encountered social exclusion and isolation, these networks were not regarded as substitutes for real-life relationships.

Analysis of the personal home pages of 16 adults with Down's syndrome revealed how friendships could be redefined (Seale & Pockney, 2002). A number of the authors referred to "cyber-friendships" which in some cases had developed into "real" friendships. There was no evidence to suggest that virtual relationships were regarded as inferior to those in real-life.

Drainoni et al (2004) conducted a cross-sectional survey (n=286) to assess the relationship between Internet use and health-related quality of life among people with spinal cord injuries, and found that there was a relationship between Internet use and a measure of social integration; however due to the method used causality can not be inferred.

Interviews with a group of people representing a wide range of disabilities were carried out by Seymour and Lupton (2004) and revealed the Internet as a valued way to develop and maintain friendships. The authors discuss the potential online for a different type of relationship, with the possibility of more expansive communication in a context not dominated by the tragedy of disability; that is obligation, dependency, competing priorities and exhaustion. However, as I shall discuss later, they concluded that this potential was not being realised by the participants in their study.

Research by Bradley and Poppen (2003) in which 20 homebound people representative of a diverse range of disabilities were provided with computer and Internet access and training, prompted the evolution of an online community via email, bulletin board and chat. At one year follow-up there was a significant increase in communication with friends, family, community services and government agencies as well as personal satisfaction with the amount of contact with other people.

Sohlberg and colleagues studied the longitudinal effects of an adapted email interface with people with severe acquired cognitive impairments (Sohlberg et al., 2005). All of the four participants became independent, satisfied mailers in

their home environments. They reported increased feelings of social connectedness and continued to engage in social email after nine months.

Through contact with personal friends online, or participation in online forums the social support opportunities for people with disabilities are enhanced. As discussed previously (see "Social support") many self-help groups exist on the Internet, addressing a wide range of issues and mimicking the social support and therapeutic processes of offline support and self-help groups (see Braithwaite et al., 1999; Finn, 1999).

For people with disabilities who have difficulty accessing face-to-face support groups, online forums can facilitate contact with a peer group, bringing opportunities for the exchange of information, ideas, discussion, advice and emotional support from first hand experience, in a context of shared understanding (Bowker, 1999; Cromby & Standen, 1999). With this may come friendships and a sense of shared identity and solidarity.

From her study, Bowker (1999) concluded that the online forum for people with a rare neurological disability (Shy-Drager syndrome) "fostered an educational and socially empowering experience" for its members. Analysis of postings on an online forum for people who stutter showed it to be a community in which participants gave advice, expressed deep often negative emotions and offered empathy (Stoudt & Ouellette, 2004). Through their collective experiences there was the opportunity for participants to develop new perspectives on themselves as individuals, their disability and its associated stigma.

Disability, identity and the Internet

According to Bowker (1999) if identity is a social construct, a product of our daily interactions with others through which we gain a sense of who we are and our role in the world, then the Internet "offers alternative themes surrounding the self." In a world which seems to be increasingly focussed on the body and visual image, the textual resources of the Internet can create opportunities for disabled people to construct more empowering identities than those which are limited by the stigma and physical or communication barriers they face in the offline world.

A recent interview study conducted by Bowker and Tuffin (2007) explored the psychological meaning of being online for people with disabilities. Their analysis revealed three ways in which participants constructed more positive subjectivities through their online interactions. Not only may they be judged on the basis of the content of their communication without the contamination of

prejudice towards disability, but the reduction of barriers to social participation may enable them to display their capabilities and to operate more independently.

Bowker and Tuffin (2002; 2003), and also Anderberg and Jonsson (2005), investigated the ways in which people with disabilities managed identity in online contexts. Their interviews revealed that online people with disabilities exercised a choice to disclose their impairment depending on the demands of the situation, for example whether it was perceived to be relevant or constructive to the interaction. This was a choice made willingly, enabling them to experience non-disabled subjectivities denied them in the physical world. Bowker and Tuffin (2003) argue that by operating in different subjectivities people with disabilities may manage the dilemma of participating in a medium which, due to its visual anonymity offers the opportunity to experience a non-stigmatised identity whilst also presenting the possibility of falling victim to the deceptive or malicious acts of others.

Analysis of the postings in an Internet-based forum for people who stutter revealed that with the fluency of communication they were afforded online, came fluid and multiple expressions of the self rather than "passive individuals experiencing disability and stigma" (Stoudt & Ouellette, 2004, p175). Online forums such as this can have the dual effect of, on the one hand enabling individual self-expression, but on the other, enhancing a sense of shared group identity through the discussion of issues pertinent to the disability. As the previous discussion of computer-mediated social support has indicated, this sense of commonality and validation could be supportive and empowering for the individuals involved.

The duality of the Internet for individual self-expression as well as the construction of group identity may also be apparent in personal home pages. Seale and colleagues explored the use of personal home pages by adults with Down's syndrome as a tool for managing identity and friendships (Seale, 2001; Seale & Pockney, 2002). Thematic analysis of 20 personal home pages suggested that, rather than denying their disability due to its associated stigma, their owners were using them to "construct and present multiple selves: a self that is similar to those with Down syndrome and a self which is also different" (Seale, 2001). This was achieved through the use of text and graphics to convey aspects of oneself such as biographical details, interests, likes and dislikes, ideas, friends and personal icons. Further analysis revealed that the owners were also attempting to portray themselves as people who were

capable of having friends, with the possibility of encouraging new online relationships to develop, by referring to existing friendships, as well as incorporating photographs, guest-books and links to other personal home pages (Seale & Pockney, 2002). This is strategic behaviour which no doubt is fundamental to the functioning of the newer phenomenon of social network sites such as Facebook and MySpace. As Seale and Pockney themselves point out, some caution in the interpretation of their analyses is warranted in view of the possibility that authorship of the home page may be by a third party. They raise the need for further exploration of what motivates and influences the construction and publication of these home pages and how people with learning disabilities may take more control in their creation.

The choice and flexibility afforded by the Internet to reveal certain aspects of oneself challenges traditional models of identity as essentially stable across time, culture and context (Bowker & Tuffin, 2002; Cromby & Standen, 1999). A postmodern model of the self as fluid and malleable to the situation could be seen as liberating for people with disabilities in the online situation as I shall now discuss.

The Internet: a tool of empowerment or segregation?

From the discussion so far there are various ways in which the Internet has been proposed as a means of liberation for people with various types of disabilities from the restrictions they face in everyday life, and indeed there is evidence to suggest that this is a perception held by members of the disabled community who use the Internet. The inference is that the Internet is a more inclusive medium for people with disabilities. However, several commentators, for example Guo and colleagues (2005), have added caution to the debate, pointing out that "the Internet's potential to eliminate discrimination exists in the context of a real-world social environment in which discrimination still prevails". It may temporarily assuage discrimination, but it cannot be the sole means by which social attitudes are overturned. Whilst research by Roulstone (Roulstone, 1998) identified the ways in which new technology can benefit disabled people in the workplace in terms of access and the realisation of abilities, it also concluded that physical and attitudinal barriers continued to exist in the broader working environment.

Anderberg and Jonsson (2005) alert us to the possibility that the benefits of the Internet for disabled people in terms of ease and convenience may evolve into self-imposed restrictions and a tendency to withdraw from life offline. However,

when Bradley and Poppen (2003) followed up the members of an online community for disabled and homebound people, they found a significant increase in perceived ability to leave the house. Despite there being no change in level of physical mobility, participants were more able or willing to go out, which the researchers suggested may have been stimulated by a desire to meet new found Internet friends in person.

Only 13% of the 122 respondents in the survey by Guo and colleagues reported less communication with family as a result of their Internet use, and only 13% thought it had decreased their participation in local community activities (Guo et al., 2005).

Some writers have suggested that the invisibility of disability online may serve to undermine its broader representation, such that "differences are denied and already marginalised voices are silenced even further" (Bowker & Tuffin, 2002, p330; see also Bowker & Tuffin, 2007). The creation of "virtual community care" for people with disabilities risks the diversion of attention away from the need to address barriers in the offline world (see Seymour & Lupton, 2004). In this way the Internet, rather than an engine for social change, could be seen as a mechanism by which the social isolation of disabled people may be exacerbated.

By shedding their disability online, the way in which disabled people identify themselves may change with a consequent loss of solidarity further limiting the potential for change through political action (Cromby & Standen, 1999). From their interviews with people representative of a wide range of disabilities, Seymour and Lupton (2004) concluded that whilst participants took part in online forums for disability, this did not serve to effect change. Talking to others who understood provided valuable comfort and support, but reinforced well engrained and discriminatory constructs of disability and isolated significant issues from the public domain. The potential to share information and instigate action for change was not being realised by this group of people. Seymour and Lupton warn that disabled people online may be seduced by "the illusion of support and control" with the risk of ghettoisation of an already marginalised group. Thus the Internet may serve as an agent of social control (see Bowker & Tuffin, 2002).

A later study by Anderberg and Jonsson (2005) however indicated that most of the people interviewed (n=22), who all had physical disabilities, had reflected on these issues. For them the Internet had increased independence, knowledge and communication which led the authors to a more optimistic view of the

Internet as an additional tool for the political struggle for a more equal and discrimination-free society. Drawing on their analysis of interviews with disabled people, Bowker and Tuffin (2007) highlight the potential for this group to exhibit their strengths and make valuable contributions to society through their online interactions, with the possibility to challenge and redefine disabled identities offline (see also Roulstone, 1998) in a more positive way which respects difference and diversity.

The disability divide

As discussed earlier (see "The digital divide"), despite its potential to improve quality of life for individuals living with disability, arguably more so than non-disabled people, Internet use is less prevalent amongst this section of the population (Disability, 2001; Dobransky & Hargittai, 2006; Dutton & Helsper, 2007; Pilling et al., 2004). This is attributable to disability specific issues compounded by other social barriers associated with disability: low income, poor employment opportunities and lack of education (Dobransky & Hargittai, 2006; Drainoni et al., 2004; Guo et al., 2005).

Dobransky and Hargittai (2006) analysed data from the Bureau of Labour Statistics and the Census of the United States to explore trends in Internet use by people with disabilities. They found that there was a disparity between home access and use. Compared to their non-disabled counterparts, people with disabilities living in a household with Internet access were less likely to be Internet users (77% compared to 88%) implying that their needs are not being fully met. Many people with disabilities require adaptive technology to overcome the particular difficulties they face going online as a result of their impairment, for example voice recognition and speech output systems, keyboard and mouse adaptations, and adaptive web browsers which can simplify layout and symbolise text. This need raises the barrier of extra cost of the necessary equipment and training, which may be considerable depending on the technology involved, to a group who already face socioeconomic disadvantage (see Pilling et al., 2004).

The issue of overcoming barriers to access is complicated by the slower pace of adaptive technological developments. As accommodations are accomplished, mainstream technology moves further ahead, and further adaptation is needed. A more proactive approach is needed aiming for the development of technology which is universally accessible from its inception. This would necessitate the involvement of people with disabilities throughout the design and evaluation

process of new technologies (Bradley & Poppen, 2003; Cromby & Standen, 1999; Dobransky & Hargittai, 2006; Hollier, 2007).

Despite the availability of guidelines set out by the Web Accessibility Initiative (2007), and contrary to the Disability Discrimination Act ("Disability Discrimination Act," 1995), an analysis of websites carried out by Curran et al (2007, p447) indicated that "irresponsible and inaccessible web design causes unnecessary problems to certain website users" particularly those living with physical, cognitive or sensory disability. Potential web usability barriers include: complicated navigation layouts, poorly designed search capabilities, cluttered web pages, complex language, and incompatibility with adaptive software or with the use of a keyboard for navigation rather than a mouse (see Pilling et al., 2004).

From the discussion it is clear that disabled individuals are disadvantaged in terms of their access to the Internet, which not only deprives them of opportunities more routinely available to the general population, but also opportunities to counteract the physical, communication and attitudinal barriers they face in the offline world as people living with disability. In this way the unequal status they face in society may be reinforced (Dobransky & Hargittai, 2006). There is a need for social policy to address the issues which contribute to this inequality, including: a proactive approach to the development of affordable and accessible technology to meet the needs of people with disabilities; the implementation of policies which require websites to be universally accessible; the development and maintenance of public Internet access points which comply with accessibility requirements; the provision of subsidies for the cost of equipment and access to disabled people on low incomes; and support to organisations who provide information and training to disabled users of the Internet (Dobransky & Hargittai, 2006; Pilling et al., 2004).

Autism and information technology

It is recognised by practitioners that many people with autistic spectrum disorders have an affinity for computers, and this has been exploited for therapeutic and educational purposes. Murray (1997) sees computers as highly compatible with the particular attention style of autistic people. They are naturally monotropic, that is, one's attention is focused on isolated objects, as though through a tunnel, separate from the surrounding context.

Other proposed advantages for autistic people (Bolte, 2004; Murray, 1997; Swettenham, 1996) are that computers:

- are rule governed, predictable and controllable
- enable safe error-making
- are highly perfectible media
- provide social and emotional distancing
- can be highly motivating

There is growing interest in the use of virtual reality with autistic people for the purposes of social and life skills training (Bolte, 2004; Mitchell et al., 2007; Parsons & Mitchell, 2002; Parsons et al., 2004; Standen & Brown, 2005; Strickland, 1997). As well as providing a safe place in which to try out skills and make mistakes, virtual environments enable stimuli to be modified to a tolerable level, and gradually altered to encourage cross-recognition and generalisation. Early indications are that this is an acceptable medium to people with ASD with the potential to rehearse real-life skills, although the prospects for generalisation are as yet undetermined.

Experimental studies on a small number of autistic subjects demonstrated that individuals can communicate via typed computer text to practice dialogue in a computer generated comic strip style role play situation, some showing performance which is hard to distinguish from matched controls (Rajendran & Mitchell, 2000).

The evolution of the World Wide Web has seen the emergence of home pages constructed by people at the high-functioning end of the autistic spectrum. By this means individuals have been able to share their personal accounts of being autistic with a potentially vast audience. Analysis of five of these sites by Jones and colleagues yielded a more complex picture of autism than can be gained from textbook accounts, one which challenged some of the commonly held assumptions about the condition (Jones & Meldal, 2001; Jones et al., 2003; Jones et al., 2001). The descriptions did not characterise autism as deficient of emotion or interest in social relationships. The authors showed great awareness and insight into their differences, articulating their desire for relationships with other people and describing attempts to "fit in" (Jones & Meldal, 2001). They expressed frustration, depression, fear, apprehension and a sense of alienation in response to the difficulties they faced in their everyday lives (Jones et al., 2001).

YouTube also provides a forum in which stereotypes maybe challenged as demonstrated by one short video which attracted extensive media attention, posted by Amanda Baggs in which her typically autistic rocking and flapping movements are juxtaposed with her extremely eloquent narration (see Biever, 2007).

Anecdotal accounts indicate that the Internet has brought new opportunities for autistic people to communicate with each other via chat rooms, bulletin boards and discussion lists (Blume, 1997b). There are also reports of a group of autistic people who participate in Second Life from a private island called Brigadoon, set up in 2005 by John Lester, a neurology researcher, as a "consequence-free place" where residents could practice social and cooperative skills (Biever, 2007).

The impact of the Internet on high-functioning autistic adults has been likened to that of sign language on the deaf community (Blume, 1997b); a tool of empowerment (Tantam, 2003). Dekker (1999), and Ward and Meyer (1999), attribute the recent emergence of autistic culture and self-advocacy to the Internet. As someone with high-functioning autism, who runs the electronic mailing list Independent Living on the Autistic Spectrum (InLv), Dekker sees it as essential to the communication of autistic adults, enabling self-expression and providing mutual emotional and practical support.

Similar to the online group for people who stutter, studied by Stoudt and Ouellette (2004), Dekker describes how the collective firsthand experiences of the InLv community provided its members with insights into the meaning of autism not commonly found in the literature, for example inertia, face blindness, central auditory processing disorder and sense of time. According to Blume (1997b) group consensus emerging from online forums for people with autism has yielded a new social construct, that of neural pluralism, by which the dominant, but not necessarily superior, neurotypical trait is only one of many neurological configurations, a concept which is reinforced in blogs and websites created by people on the autistic spectrum.

In contrast with the image of people with autism as being unable to speak for themselves, analysis of their postings to an online discussion group over a four month period indicated that they were finding a voice in the online environment (Brownlow & O'Dell, 2006). Two major themes characterised their discourse in the online discussions: the role of autistic people in contrast to professionals as experts regarding knowledge of the condition, and the construction and

exploration of an autistic identity, positioned as at least equal to neurotypical people.

As well as greater potential to find a supportive and empowering peer group, it may be that for autistic people the Internet also offers a more comfortable space in which to communicate, perhaps one in which their interaction seems less odd. Interestingly the Internet seems to provide autistic people with metaphors to describe their thought processes. Temple Grandin for example says "…nothing out there comes closer to the way I think than the World-Wide Web" (Blume, 1997a). The perception of the Internet as a valuable communication channel for people with autism emerged from the personal home pages analysed by Jones and Meldal (2001) and also, more recently, interviews with high-functioning autism about their experiences navigating their social worlds (Muller et al., 2008). Drawing on knowledge of the characteristics of autism and anecdotal reflections (Biever, 2007; Blume, 1997b; Singer, 1999), there are various features of computer-mediated interaction which could bypass the social communication difficulties of autism (see also Breda):

- Lack of nonverbal social context cues
- Use of emoticons and other strategies to make some nonverbal aspects more explicit.
- A single channel, easier to focus on
- A different rhythm and slower pace of communication
- A more constant and predictable environment.
- Lack of necessity for face-to-face contact
- Anonymity and safety to try out new social skills and "shop around" for social contact

There is a suggestion that electronic forms of communication such as email and instant messaging may ease emotional expression for some people with Asperger syndrome who struggle to express their emotions through speech, and may therefore be incorporated into cognitive therapeutic interventions with such individuals (Anderson & Morris, 2006; Attwood, 2003).

Some commentators (Baruch, 2001; Singer, 1999) have noted the parallels between online and autistic communication and have suggested that the term autism may be used as a metaphor representing the implications of information technology, particularly the Internet, for society. Pervasive use of rule-based logical technology, which lacks neurotypical emotional cues, may possibly

create a society more autistic in nature than previously. Baruch (2001) takes a somewhat negative view of an "autistic" technology orientated society, warning us of the risk of becoming "a global village of poor communicators." Singer (1999, p130), however, is more constructive in her approach to the issue, highlighting the potential for a society "that is more relaxed about different styles of being, that will be content to let each individual find his/her own niche."

However, along with opportunities for interaction the Internet also brings risks. Autistic people may be particularly vulnerable to individuals misrepresenting themselves. Howlin (1998) reflects on the possibility of over-reliance on computer interaction resulting in an exacerbation of obsessive behaviour and withdrawal from face-to-face interaction.

In writing Chapter 2 and this chapter I have contextualised the need for research into the use of the Internet as a communication medium by people with high-functioning autism or Asperger syndrome. A consideration of the features of ASDs as well as the characteristics of CMC, suggests the potential of the Internet as a comfortable communication medium for high-functioning autistic people. Anecdotal reports indicate that this is the case. However there is a need to initiate empirical research into this area. This study constitutes the first in depth exploration of the use of Internet-based communication by people with HFA or AS, a community which, typically, is socially marginalised, isolated and under-employed.

To reiterate, the research question, aims and objectives for this study are as follows:

How do people with high-functioning autism (HFA) or Asperger syndrome (AS) experience the Internet as a communication medium?

Aim 1

To explore the ways in which the Internet is being used for communication by people with HFA or AS

Objectives

- To find out how access to the Internet is obtained by people with AS or HFA
- To find out the amount of time being spent online by people with AS or HFA and the level of satisfaction with this quantity

- To place CMC use in the context of other forms of Internet use, computer use, social contact and communication
- To explore the reasons why people with AS or HFA use the Internet for communication

Aim 2

To explore the experiences, motivations and perceptions of people with HFA or AS who use the Internet for communication

CHAPTER 4: METHODS

Research strategy

In identifying an appropriate methodological approach towards a social research question consideration should be given towards the overarching and interconnected assumptions about the nature of reality upon which researchers seek to build knowledge. This set of postulates (or the research paradigm) guide the research process: the formulation of the research question and the methods for collecting and analysing data (Maykut & Morehouse, 1994, chapter 2).

The definition of two contrasting research paradigms based on fundamentally different assumptions is accepted by many writers as the basis of the quantitative and qualitative research distinction. Maykut and Morehouse (1994) refer to these as the traditional paradigm based on a positivist position (Lincoln & Guba, 1985) and the alternate paradigm which takes a phenomenological position. There is much debate as to whether the philosophical underpinnings to these approaches are such that they are mutually exclusive, precluding the possibility of a complementary "mixed methods" approach, and, depending on one's viewpoint, bestowing supremacy on one strategy over another (Bryman, 1984).

The traditional paradigm

Traditionally the quantitative approach has been associated with the positivist position and is based on a realist view of the world, that is, the belief that a reality exists independently of the observer and as such can be studied objectively. The positivist position advocates the application of natural scientific methodology to the objective study of social reality.

Based on these assumptions quantitative research is concerned with quantification in the collection and analysis of data, and conceptualises the relationship between theory and research as deductive, such that the testing of preconceived hypotheses is core to the approach. The desired outcomes would be explanation, prediction and proof of observable events. Therefore validity, reliability and generalisability are also key aspects of quantitative research to

be achieved through structured and systematic methods of data collection and representative sampling. The assumption is that the researcher remains detached and objective, in order to avoid contamination of data and that causality may be identified through the isolation or control of variables.

Critics of the positivist position would challenge the premise that the methods of the natural sciences can be applied to social phenomena. They argue that in contrast to objects of the natural sciences, the capacity of people for self-reflection cannot be ignored (Bryman, 2001). As Murphy and Dingwall (2003, p10) point out "knowledge always rests on some point of view - on some mixture of the observer's prior knowledge, experience, values and motives with their biological and technical capacities." It is also debatable as to whether social behaviour can be simplified into distinct variables and whether measurements are made on arbitrarily defined bases. Hence there are limits to what can be achieved by a quantitative approach, and the risk is that the outcomes of this research strategy may present an over simplified version of the social reality or even a misleading one.

The alternate paradigm

Drawing on Kuhn's work on the history of science (Bryman, 2001; Maykut & Morehouse, 1994) some see the development of the alternate paradigm, on which qualitative methodology is purportedly based, as a natural consequence of the emergence of anomalies in the findings of traditional research methods. This position takes a phenomenological stance that aspects of the social world can only be understood from the actors own perspectives. The role of the researcher is to interpret the subjective meaning of social action. The assumption is that the important reality is what people perceive it to be (Kvale, 1996). This view is rooted in constructionism which asserts that social phenomena and their meanings are continually being accomplished by social actors (Bryman, 2001). However according to Foucault (see Holstein & Gubrium, 2004, p149) meaning is not constantly formulated anew, but reflects "relatively enduring local contingencies and conditions of possibility". The extreme interpretation of this constructionism (radical constructionism, see Murphy et al., 1998) is that reality is created only in our minds. It is therefore possible for multiple and competing "truths" to exist with equal authenticity. From a social constructionist point of view people's perceptions and actions are dictated by membership of particular social or cultural groups. When people interact, they do so with the understanding that their respective perceptions of

reality are related, and as they act upon this understanding their common knowledge of reality becomes reinforced.

Qualitative researchers share the belief that their methods can produce a deeper understanding of some aspects of the social world than would be possible from a quantitative approach (Silverman, 2001). Research is conducted in a natural setting where the researcher is the instrument of data collection (Lincoln & Guba, 1985). The "human as instrument" is viewed as being flexible enough to capture the complex, subtle and dynamic nature of social phenomena. Data are obtained in the form of words or pictures, rather than numbers, and the analytic process focuses on meaning. Rather than isolating and manipulating variables a holistic approach is taken in which the phenomenon of interest is studied in context and detail.

Criticisms of qualitative research are often rooted in the traditional paradigm, and hence relate to a lack of validity, reliability and generalisability due to the status of researcher as instrument of data collection rather than detached observer, and also representative sampling being frequently unavailable owing to the complexity and depth of investigation. Those who reject the positivist position would argue that such dimensions do not constitute an appropriate framework by which the quality of research can be evaluated. Whilst some would reject these criteria outright, others have offered alternative concepts such as trustworthiness which is concerned with the transferability, credibility, dependability and confirmability of the research findings (Lincoln & Guba, 1985). However Murphy and Dingwall (2003, p173) point out the inherent inconsistency of attempts to establish trustworthiness whilst conceptualising a world of "multiple constructed realities."

Although Murphy and Dingwall (2003) do not adhere to a positivist position, they criticise the underlying constructionist position firstly for being self-refuting: if all truths are socially constructed then this claim in itself must also be a construction, other conflicting interpretations being possible. Secondly our interpretations of the world can be challenged by what Blumer (1969, cited in Murphy & Dingwall, 2003, p12) calls the "obdurate character of the empirical world"; our experiences of the world do not bear all possible interpretations we may apply to it. The constructionist model of the social world is also criticised for its implausibility, due to a lack of common referents such that we would live in separate and distinct realities precluding any possibility of interaction and communication.

Subtle realism: An alternative to the two paradigm approach

The discussion so far has yielded two apparently incommensurable approaches to the investigation of social phenomena, each with their apparent limitations. Hammersley (1992) proposes an alternative view, one which acknowledges the role of psychological and social influences on our understanding of the world. Based on subtle realism, this approach accepts that there is a world existent independent of its observers. However knowledge of this world is a "joint product of the referent and the cultural-biological lenses through which it is seen" (Campbell 1994, cited in Murphy & Dingwall, 2003, p13). As such our observations of the world can not be assumed to be objective; they are subject to our interpretations and the prior influences we bring to the situation. The subtle realist position acknowledges that several representations of reality are possible. However, in contrast to the constructionist view, the possibility of contradictory truths is excluded, and judgements of authenticity can be made based on evidence and debate. It is the work of the researcher to rigorously test and evaluate claims. This is not to say there is an absolute truth as such (Hammersley, 1992) rather there is an acceptance of "the possibility of specific local, personal and community forms of truth with a focus on daily life and local narrative" (Kvale, 1996, p231).

Generalisability and validity

Hammersley (1992) proposes two criteria on which generalisability may be judged in qualitative research: empirical generalisability and theoretical inference. Empirical generalisability may be assessed through reference to published statistics to establish the typicality or otherwise of the research setting. Where such information is not available, a survey may be incorporated into the research design as a means of verifying the representativity of qualitative findings. Alternatively generalisability could be assessed through the combination of studies in a range of different research settings.

Some authors however would argue that it is the transferability (Lincoln & Guba, 1985) of research findings, rather than their empirical generalisability, which is possible under the qualitative paradigm. By providing detailed description of the research setting and participants, the researcher allows the reader to judge the applicability of research findings to other settings.

The second condition for the generalisability of qualitative research, theoretical inference, is based on the applicability of findings to theory (Bryman, 2001) rather than to populations. It is argued that this can be achieved through

theoretical sampling (sampling on the basis of concepts which have proved to be theoretically relevant to emerging theory, see Murphy et al., 1998) and analytic induction (a systematic search for falsifying evidence and negative cases such that theory is modified until no further disconfirming evidence can be found, see Murphy et al., 1998).

Whilst accepting that respondent validation and triangulation are methods which can yield additional data for analysis, Murphy et al (1998) reject the claim that they are indicators of validity. Based on the assumption that any phenomenon can be interpreted from a range of varying viewpoints, they propose that the validity of qualitative research findings may be judged (although never proved beyond doubt) on the basis of their success in limiting error. This may be achieved through the attention given to negative contradictory cases and the range of alternative perspectives, the clarity and detail of description of the methods of data collection and analysis, and awareness of how the researcher's presence and pre-existing assumptions may have shaped data collection and analysis.

A pragmatic approach

By taking the subtle realist stance we can accept that both qualitative and quantitative methods are committed to finding truth, and indeed may be combined for this purpose, but that neither can claim to find uncontaminated truth. Rather than a commitment to one set of assumptions over another, a more instrumental approach to one's choice of research method can be taken, based on pragmatic grounds. What is more important is the purpose of the research and to identify the means by which the research question can be answered most effectively and efficiently (Hammersley, 1992). Referring to the philosophy of pragmatism, as pioneered by theorists such as John Dewey, Yardley and Bishop (in press) declare: "Pragmatism addresses the concerns of both qualitative and quantitative researchers by pointing out that all human inquiry involves imagination and interpretation, intentions and values, but must also necessarily be grounded in empirical, embodied experience." In common with subtle realism, pragmatists see knowledge and truth as grounded in an external reality, but truth is defined in a particular context, with regard to a particular goal rather than a universal, objective truth.

As such, a pragmatic approach based on subtle realism has permeated the design of this study, ensuring methodological congruence (Morse & Richards, 2002) in the formulation of the research question and aims, as well as the

choice of methods for data collection and analysis. I shall now discuss how this approach informs the methodology adopted for this study.

A combined research methods design

In defining the questions, aims and objectives which guide this piece of research (see Chapter 3), I am acknowledging a belief in the existence of the social phenomenon, some aspects of which require more interpretation than others as knowledge is attained. For example I would suggest that issues of motivation and perception around the topic of online communication are subject to a greater degree of construction than issues of time spent online and place of access. The need for varying degrees of interpretation as well as some breadth yet at the same time depth of knowledge led to the combination of quantitative and qualitative methods in tackling the research question with the aim of producing a richer more complete description of the phenomenon than would be possible by a single paradigmatic approach. However as Yardley and Bishop (in press) note, "it should never be assumed that the insights derived from these methods will necessarily converge". They offer the term "composite analysis" to encapsulate the way in which separate findings from different methodological approaches can be integrated with the "potential to yield complementary insights" generating a whole greater than the sum of its parts.

The first research aim was addressed by a cross-sectional survey of adults with HFA/AS. Data were collected by means of web-based or postal questionnaire. As well as providing a breadth of contextual information around the phenomenon of Internet-based communication and HFA/AS, it also raised issues which could be followed up in more detail and depth in the second part of the study, in which a subset of the survey sample were interviewed by email, to address the second research aim. The survey also provided data which guided the selection of interview participants to obtain maximum variation (Maykut & Morehouse, 1994) in terms of personal demographic factors, as well as Internet-based communication factors such as frequency of use, format used, place of access and personal communication preferences. Information on communication preferences obtained from the survey also indicated the use of email as the interview format. However to ensure that the views of non or reluctant users of the Internet were obtained, the researcher exchanged, by conventional mail, a series of open questions and responses with a small number of respondents who fulfilled this criterion.

The quantitative study

Participants

Criteria

For the purposes of this research diagnoses of HFA and AS were both acceptable. As was discussed earlier, these terms are often used interchangeably, and any early differences in cognitive or language development, which constitute the official distinguishing criteria, are minimal by adulthood. Both groups, being of normal intelligence, should comprise people to whom the Internet is potentially accessible, given that they are of normal intelligence, but who nevertheless have difficulties affecting social interaction and communication. As this was to be a postal or Internet survey aiming for 200 volunteers, in depth diagnostic checks were not feasible. However respondents were asked if they would be prepared to receive a follow up questionnaire, which measures autistic traits in adults of normal intelligence (see "The autism-spectrum quotient (AQ)").

In terms of age the study was aimed at adults of 16 years and over.

Sampling

The desired sample size was 200 including a minimum of 50 non-users of the Internet. Whilst services for people with autism and additional learning difficulties are increasing, specific provision for people with Asperger syndrome or HFA is less available. They do not fit easily into mainstream support services and many live within the community with family support, unrecognised by health or social services (Barnard et al., 2001; Howlin, 2000; 2003; Macleod, 1999; Tantam, 2003). Therefore to obtain a sufficiently large sample reflecting diversity in terms of age, sex, ethnicity, employment and residential status, participants were recruited via a number of different organisations.

Reference to the literature, key researchers and professionals in the field of AS and HFA yielded the following as possible sources of respondents, each one having its own strengths and limitations:

- National Autistic Society (NAS)
- Regional affiliated autistic societies
- FE colleges/universities (via learning support teams)
- Psychiatric services

- Clinical psychology services
- Specialist diagnostic clinics
- Social services
- Residential providers – NAS/affiliated
- Day centres/support services – NAS/affiliated
- School psychology services
- Specialist schools and colleges
- Social/support groups for people with AS/HFA
- Specialised employment agencies
- General media
- Specialised media
- Internet newsgroups, bulletin boards and websites for people with autism

Given the comments above, health and social services were not approached as they were not likely to provide access to many HFA or AS adults. Specialised diagnostic clinics were not approached initially, as they are often associated with key researchers in the field of ASD, and it was probable they were over researched.

The NAS and the local affiliated autistic society were contacted, but could not offer direct access to potential volunteers due to data protection issues. However the NAS offered to place a short article in their magazine calling for volunteers. Although this has a high distribution rate, it does not necessarily reach a large number of HFA or AS adults as NAS membership is largely composed of parents of autistic children and interested professionals. To supplement this advertising, other publications were identified, with smaller circulations but which were produced by charities and organisations specifically for people with autistic spectrum disorders. Editorial staff were approached and were also agreeable to include an article about the project. Although the national general media could potentially reach a large section of the general population, it was felt that they could be difficult to access, and may incur advertising costs. Also it was not clear whether they would elicit a substantial response.

Internet advertising was also used, via websites and online groups for autistic people. These had the potential to reach a lot of participants and may yield a good response given the nature of the communication medium and the target population. However it would inevitably produce a sample biased toward Internet users. To balance this bias, a number of further and higher educational establishments, specialised educational providers and support groups were contacted. In the first instance these were locally based organisations to allow for the possibility of face-to-face liaison if required; however a limited local response prompted the geographical range of such contacts to be extended. Recognising that these local organisations may consist largely of younger autistic people who do not live in supported accommodation, other specialised employment, residential and day support services were approached to enhance the diversity of the sample. As there was little such provision locally, and because these services were not necessarily specific to HFA or AS, contact was made to organisations which were further afield, based on a list provided by the NAS.

Recruitment procedure

Based on the above approach, organisations were contacted by letter (see Appendix A) or email, and some follow up telephone calls were also made. Those who were amenable to assist in the recruitment of volunteers, did so by displaying posters or fliers advertising the project (see Appendix B), by placing articles calling for volunteers in relevant publications (see Appendix C), or by distributing questionnaires to interested parties.

Respondents to publicity material contacted the researcher by telephone, email, letter or fax for further information or to volunteer.

Research instruments

Development of the Internet Questionnaire

Design considerations

With the objectives defined by Aim 1 in mind, a questionnaire was designed. To plan the scope of its content, reference was made to other published surveys of Internet use (Marshall, 1998; Moody, 2001; Rainie et al., 2000; Scealy et al., 2002; Weiser, 2001) as well as the 2001 Census for England and Wales (Office for National Statistics, 2001).

Questions were organised into six sections as follows:

1. Using computers
2. Using the Internet
3. Communicating with other people over the Internet
4. Communicating with people in general
5. Hobbies and leisure activities
6. About you (demographic details)

The intention was for questions to follow a logical flow and to start with items more directly related to the identified research topic, to establish the credibility of the questionnaire. Filtering instructions were incorporated to facilitate progress through the questionnaire, avoiding unnecessary answering of irrelevant questions.

Mostly information was solicited through closed questions which facilitates standardisation of responses, with less potential for error due to the influence and variability of the researcher when coding for data analysis. Closed questions can also reduce the burden on the respondents by clarifying the information sought by the question and helping them to express their answers. Selecting a response from a choice is easier than having to put one's thoughts into words. This is particularly relevant given the communication impairments characteristic of autism. As de Vaus (2002) points out open questions may be more problematical when a written response is required as opposed to a verbal one. It should be noted however that this may not be the case for people with autistic spectrum disorders some of whom may find written expression preferable to face-to-face communication.

It should be acknowledged however that closed questions can be invalidated if the answers offered do not adequately cover the range of possibilities or are open to misinterpretation. These issues were addressed by the inclusion of "Other – please give details" as a response option, and meticulous attention to wording.

Clarity and precision of expression are additionally important when designing a questionnaire for people with HFA or AS who may be confused by non-literal or abstract language.

Whilst most questions were categorical in nature, others were ordinal. Ranking questions were used, for example, to indicate the relative amounts of time

spent on different computer or Internet activities. Attitudes to Internet communication were measured by a series of Likert-style rating questions where the respondent was asked to identify how much they agreed or disagreed with a particular statement.

On the final page of the booklet respondents were asked if they would be interested in any of the following:

- A copy of the summary of results
- A second follow up questionnaire (the autism spectrum quotient)
- Involvement in an online interview as part of the second stage of the study (Aim 2)

The pilot process

Given that this was a newly designed questionnaire to be completed by a specific group, it was imperative that it should be tested to eliminate poor design features and to determine the length of completion time. The questionnaire was subject to three sets of revisions in the course of piloting, resulting in the final version, as shown in Figure 1.

Pre-pilot discussions

The questionnaire was shown to two educational professionals working with people who have autistic spectrum disorders. It was felt that on first impressions the questionnaire seemed long and complicated and would be off-putting to the group in mind. The complexity of filtering and the length of questionnaire are also pertinent factors in design given that this would be in part a postal survey. Therefore the sections were reordered and the document divided into four separate shorter questionnaires.

Respondents would proceed to the next questionnaire depending on their responses to the final questions of the previous one. The aim was that the process of completion would be as smooth as possible, particularly for those respondents with little or no computer/Internet experience for whom a lot of questions would not be applicable. It became apparent that while some group members would be able to fill out the questionnaire independently some would feel more confident doing so with a helper.

Further consideration by the researcher, of the increasing diversity of work situations, also led to the addition of "(including working from home)" to the "At work" option for the places in which computers were used.

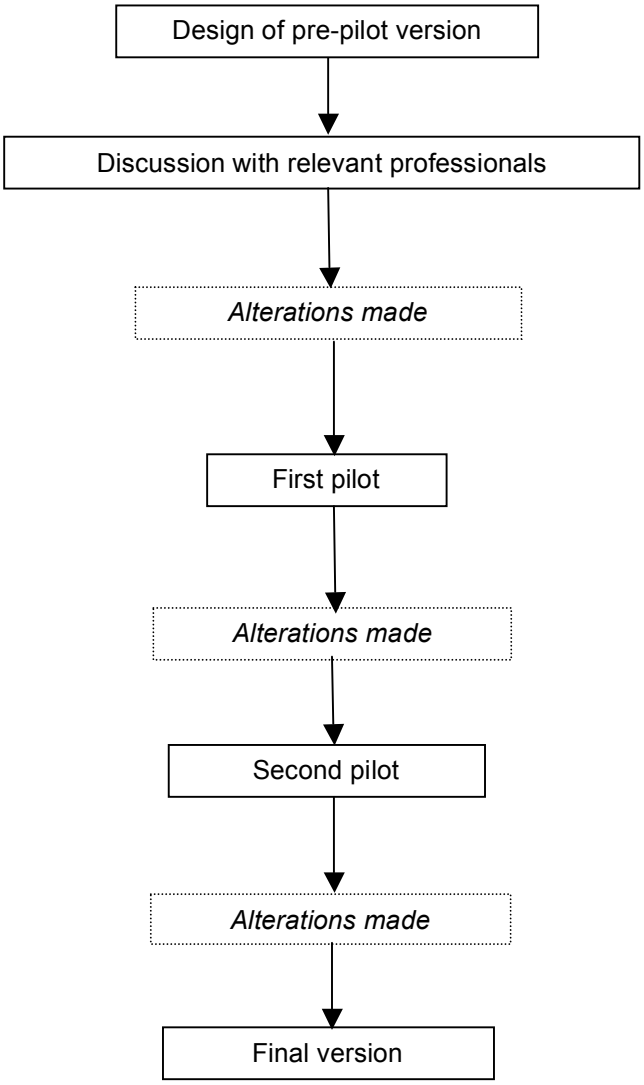


Figure 1. Development of the Internet Questionnaire

The first pilot

The first group to pilot the questionnaire were 5 members of an independent living and social skills group for young people with Asperger syndrome or autism, organised by a local further education college. The researcher attended one of the weekly evening meetings and after being introduced by the group organiser, gave some background information to the project and the pilot stage. Two group members completed the questionnaire on their own, and three opted for some assistance from a helper, one individually and two as a pair. It took between 15 and 25 minutes for the questionnaires to be completed. Some verbal feedback was obtained from the group, although this

was quite limited, a reflection perhaps of the social interaction, communication and motivation impairments characteristic of autism.

As a result of the feedback obtained from members and staff, my observations during the session and subsequent examination of the completed questionnaires, the following issues emerged for consideration:

- There was too much repetition
- Overall it was a little too long and complicated
- There was some confusion as a result of the differentiation between work/study and other locations
- Ranking type questions were confusing
- There was a need for more response options of don't know or never for some questions

With these in mind, and also as a result of further reflection by the researcher, the following amendments were made:

- The distinction between work/study and other locations was made only for questions relating to the amount of time spent on computer activities rather than those relating to the type of computer activities engaged in
- Ranking questions were replaced by Likert scale rating questions
- Don't know and never options were added to the response sets for some questions where appropriate
- Questions were added about the desire for more opportunities to use computers or the Internet access the Internet
- The questionnaire was organised into three sections each printed on a different colour of paper to ease navigation

Second pilot

In light of the alterations made it was necessary to carry out further piloting of the questionnaire. Two people were recruited for this, one a student at a local FE college, and the other was the first person to reply to a call for study volunteers published in the National Autistic Society magazine. Completion time was around 15 minutes. The changes made seemed to ease progression through the questionnaire, and most confusions had been addressed satisfactorily. However inconsistencies in responses to the series of questions about computer use highlighted that the distinction between function and place

of use was not clear, hence these questions were reworded for the final version. Also the items listed on the Likert scale set of questions were spaced out as scanning across such a large list caused some difficulty (see Appendix D for the final version).

The web-based version

The web page version of the questionnaire (see Appendix E for sample extracts) was produced by a member of the IT support staff attached to the researcher's university department, and as far as possible adhered to guidance on web survey design obtained from Dillman et al (1998) and Dowling (2003). The questionnaire commenced with an introductory page, containing a welcoming message, brief background information to the project and online questionnaire, and instructions for procedure to the next page, with a link to the volunteer information sheet (see Appendix F). Further specific instructions as to how to take the necessary computer action in order to answer questions were provided at the point of need in the questionnaire itself rather than on the welcome page.

Close attention was paid to ensuring consistency of content, wording and format between the paper and web versions, for example a radio button response format was used rather than drop-down boxes. Not only are the latter dissimilar to the paper and pencil format, but as Dillman (2000, in Dowling, 2003) suggests, their use may be associated with increased drop out rates as respondents find it harder to gauge their rate of progress through the questionnaire. Also, despite the technological means available which would prevent respondents from moving on until they had provided an answer to a question, the option to not respond to a question available on the paper questionnaire was maintained for the web version, to minimise meaningless responses and/or dropout.

One aspect for which a compromise was made between close adherence to the paper and pencil version and pragmatic issues of online presentation, was the use of an interactive design. Although the appearance of the questionnaire on one page, with the use of the right hand scroll bar for navigation, would be more similar to the paper version, the length and complexity of filtering associated with this particular questionnaire was such that an interactive design was more appropriate. Thus groups of questions were presented screen by screen, respondents using a submit button to bring up the next screen once they were ready to do so. This format also facilitated automatic filtering to

guide the respondents through the questionnaire, so they were saved the frustration and potential for errors involved in scrolling past questions they were not being asked to complete to find their next question. Although such a multiple page design involves a longer time for completion, experiments have indicated it yields a lower item non-response than a scrolling single page design (Manfreda et al, 2002, in Dowling, 2003).

The disadvantage of the interactive design is that respondents cannot see the entire questionnaire and thus are unable to determine their rate of progress toward the end, with the risk of drop out. To counteract this, a "progress bar" was incorporated into the design, which indicated an estimate of how far through the questionnaire the respondent was at any particular point.

Data obtained from each respondent online were used to automatically populate a password protected spreadsheet from which data were exported to an SPSS database, along with data from the paper version for analysis.

Once compiled the web version was tested out by the researcher and colleagues for problems with page design, navigation, content and links.

The autism-spectrum quotient (AQ)

The AQ is a brief, self-administered assessment instrument, designed to measure autistic traits in adults of normal intelligence (Baron-Cohen et al., 2001). Although this does not constitute a full diagnostic assessment, it should give an indication of whether the respondent actually falls within the target group through comparison with earlier studies.

The AQ comprises 50 Likert scale items assessing the triad of impairments and other areas of cognitive abnormality characteristic of autism:

- Social skill
- Attention switching
- Attention to detail
- Communication
- Imagination

For each item a score of one point is allocated if the respondent's answer indicates autistic-like behaviour either mildly or strongly. In developing the AQ, Baron-Cohen et al (2001) demonstrated construct validity and also face validity in that people with AS or HFA scored highly on it (mean score of 35.8, s.d.=6.5 compared to a control group mean score of 16.4, s.d.= 6.3). Additionally items

purporting to measure each of the five domains scored moderate to high in terms of their internal consistency. Test-retest reliability was excellent.

From their initial investigations, and based on the principle that a useful cut-off should discriminate between people with AS/HFA and non autistic controls with as many true positives and as few false positives as possible, Baron-Cohen et al (2001) suggested that a score of 32 was indicative of autistic traits to a clinically significant degree within the general population. However, although this threshold yielded a false positive rate of only 2%, it also failed to identify 20% of the clinical group as having a significant level of autistic traits.

Referrals made to a diagnostic clinic were screened using the AQ by Woodbury-Smith et al (2005) who established a mean score of 35.6 (s.d.=6.6) for those who were subsequently diagnosed with AS on the basis of detailed interview with two clinicians, results which were comparable to that for the clinical group in the study by Baron-Cohen et al (2001). Those who were not diagnosed as having AS produced significantly lower scores (mean=26.2, s.d.=9.4). However this study indicated a more conservative discriminatory threshold score of 26, although again this yielded a high false negative rate of 17%.

Taken together, the studies by Baron-Cohen et al (2001) and Woodbury Smith et al (2005) indicate that, regarding the AQ, the use of a cut-off score to identify people who have a clinically significant level of autistic traits may exclude a large proportion of those with AS/HFA. Therefore, for this study, comparisons were made between the mean AQ score of the survey respondents and those reported by Baron-Cohen et al (2001) and Woodbury-Smith et al (2005), as well as indicated by other studies of clinically diagnosed groups which have all yielded similar mean scores, for example 36.4, s.d.=7.1 (Baron-Cohen et al., 2003), 34.6, s.d.=7.3 (Baron-Cohen et al., 2005), 36.5, s.d.=8.0 (Wheelwright et al., 2006), 37.3 and 36.8 (Ring et al., 2008).

Following the same principles which guided the design of the web version of the Internet Questionnaire (for example consistency of content, wording and format, and clarity of instructions) the AQ was also adapted for Internet access.

Administration of the questionnaire

A mixed mode of administration: implications for sample size and diversity

Postal and electronic modes of administration were chosen for various reasons, including low cost in terms of time and travel with the potential of reaching more participants than surveys conducted via personal contact. Web surveys

have the benefit of being quicker in terms of data return. Postal surveys however can be very slow.

Although personal contact surveys elicit a better response rate for general population samples, mail surveys (and also by inference Internet surveys) are seen as being as effective when a specific group is targeted, as is the case here, especially when the research topic is of particular relevance (Dillman, 2000; Herberlein & Baumgartner, 1978). In this study the fact that people volunteered to receive the questionnaire may have improved the rate of response. The modes of return by electronic means or by prepaid envelope were implemented to ease the burden on participants, thus encouraging a better response rate. It was also surmised that given the social communication difficulties of the study group, these modes would encourage a better response rate than face-to-face or telephone interviews with a stranger, and may be less stressful on respondents, influencing the quality of data collected.

Lack of personal contact means that respondents are less susceptible to social desirability considerations or interviewer characteristics influencing the validity of answers given (although it is debatable as to the significance of these matters to this particular population). Also there is no possibility of contamination of results due to interviewer interpretation. However there is the possibility of people other than the respondent influencing the answers given. Indeed the identity of the person completing the questionnaire can never be certain.

Two modes of questionnaire administration were used to enhance sample access and response rate. Postal questionnaires would be more widely accessible than an Internet version, and were particularly important to enable non-Internet users to respond. The web-based alternative however may have more appeal, and be more convenient, to some people, thereby enhancing the response rate. It is proposed by some writers that offering an alternative response mode enhances response rates (for example Goyder 1987, Groves and Kahn 1979, see Schaefer & Dillman, 1998).

It is possible, however, that the two modes will produce different responses if they are associated with respondent differences, for example if Internet access is associated with higher socioeconomic class. This must be taken into account when interpreting the data.

A mixed mode of administration: implications for research validity

Whilst a two mode strategy may enhance the diversity of the sample obtained, the different methods of administration may influence the way people respond, thereby affecting the validity of data. However these modes of presentation are similar in that both are self-administered, text-based, and occurring in the absence of a personal interviewer and as such Dillman et al (2001) predict this would limit mode effects. Their experiments showed respondent behaviour to scalar response type questions in a web-based questionnaire tracked closely results obtained for a corresponding postal questionnaire. Other studies (for example Davis, 19991999; Riva et al., 2003) have shown comparable internal consistencies between web and paper and pencil versions of the same questionnaire. In the current study, as already described, every effort was made to ensure the content, wording and format of the web version was as closely matched as was possible to that of the postal version, to minimise the impact of any mode effect.

However response equivalence between formats may depend on the variables involved. Several studies involving less sensitive topics, for example job satisfaction, have yielded a pattern of no difference between computer and paper and pencil self-administered questionnaire formats (see Knapp & Kirk, 2003 for a list of examples). However in his review of Internet behaviour and virtual methods, Joinson (2005) observes that experimental evidence indicates that high self-disclosure and low social desirability (that is people are less likely to present themselves in a positive light) characterises respondent behaviour in computerised research compared to offline formats, particularly when sensitive topics are involved. The questionnaire involved in the current study does not probe into sensitive areas and as such this would minimise the mixed mode effect.

Joinson's own experiments (Joinson, 1999) suggested the online format of a questionnaire encouraged greater honesty of response compared to paper and pencil version, a finding which he proposed was due to differences in perceived anonymity. However as Herroro and Meneses (2005, p832) suggest such "naïve misconceptions of computers might disappear whenever familiarity with computer technology increases". Their comparative study involving two questionnaires of a more personal nature (short versions of the Perceived Stress Scale and the Center for Epidemiological Studies-Depression Scale) showed that when familiarity with Internet technologies was high, respondent behaviour in web-based and paper and pencil formats was virtually equivalent.

Similarly, Knapp and Kirk's (2003, p133) investigations suggest that "using self-administered questionnaires with populations familiar with contemporary technology will result in equivalent results regardless of the method (pencil and paper, touch-tone phone or Internet) or the sensitivity of the questions."

In the current study, respondents were given a choice of response format, and indeed due to the delay in availability of the web-based version, this choice was initially one between waiting for the Internet version or receiving the postal version without delay. As such it seems likely that the people who opted for the web version were comfortably accustomed to the technology involved and were therefore less likely to alter their response behaviour online. Analysis of the subset of the sample who completed their questionnaires online indicated a high level of Internet use by this group (see Figure 2): 60% who completed the web-based questionnaire were spending 20 hours per week or more on the Internet.

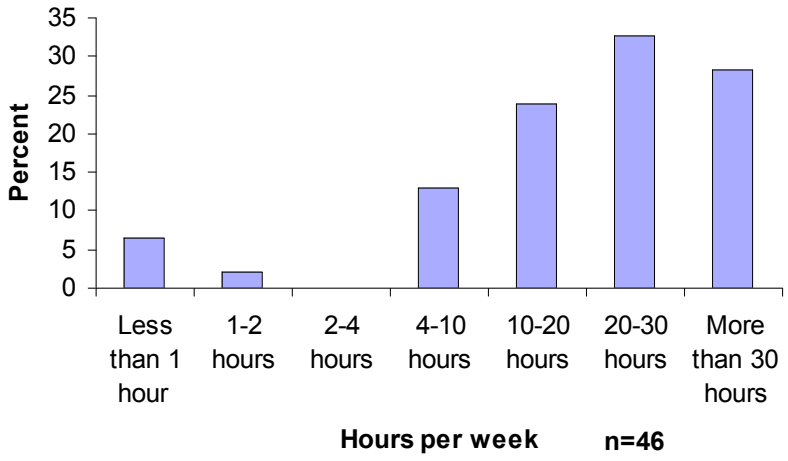


Figure 2. Time spent on the Internet by respondents who completed questionnaire online

Procedure

Participants were provided with an Internet questionnaire, information sheet (see Appendix F) and prepaid envelope, by post or via personnel at participating organisations. Alternatively, volunteers were sent the URL and an individualised password for the web version of the questionnaire/information sheet if preferred. The password was authorised for single use only, to control access and discourage repeated participation. Questionnaires were assigned a unique identifying code number to enable follow up of non-respondents (by post or email, once only within 2 to 4 weeks of dispatch). Distributing personnel were asked to record the names of the people and the ID number of the

questionnaire given, on a form to be returned to the researcher. This was to help track the response rate and any duplication which may occur.

For those who volunteered to complete the AQ, the questionnaire was sent either by post with prepaid envelope, or alternatively the URL and password for the electronic version was provided.

Ethical issues

The study was reviewed and approved by the University of Nottingham Medical School Ethics Committee (see Appendix G).

All respondents were provided with an information sheet (see Appendix F) explaining the purpose of the study, methods involved, dissemination of results, researcher's contact details, complaints procedure as well as their rights to privacy, confidentiality, withdrawal from the study and security of data storage.

The vulnerability of this group must be considered. It was made clear on the information sheet: that participation was on a voluntary basis; that respondents were free to pass over questions they did not wish to answer; and that they may withdraw at any time and without giving a reason. As people with high-functioning autism or Asperger syndrome tend to be of normal intelligence, respondents were assumed to be competent to give consent unless there was evidence to the contrary. Mild cognitive impairment should not prevent a participant from making a competent choice (Royal College of Physicians, 1990). Completion and return of a questionnaire by a voluntarily recruited respondent was taken as informed consent.

All personal identifying information was kept separately from completed questionnaires and links between the two coded. Computer database files were password protected and completed questionnaires were stored in locked cabinets. Personal identifying information was not disclosed in the reporting of results.

Data analysis

Status of the data

As already discussed, there were difficulties accessing the target population, which necessitated a non-probability approach to sampling, with the possibility of sample bias. Given the research topic, it is also possible that the inclusion of a web version of the questionnaire biased the sample obtained toward Internet users, who are more likely to be younger, more highly educated or higher earners (see "The digital divide," Chapter 3). Whilst conclusions and

generalisations can not be made with respect to the HFA/AS population, information about subgroups was obtained and comparisons made, and possible relationships between variables were hypothesised. Analysis of the survey data therefore enhanced discussion and understanding of the research topic and suggested directions for further investigation (in particular a guide to topics to pursue in the subsequently planned interviews).

Univariate analysis

The first task was to describe the characteristics of the sample of respondents which had been obtained via the methods of recruitment. Various personal/demographic characteristics were profiled, and illustrated via frequency tables or graphs (bar charts or pie charts) as well as measures of central tendency (mode, median or mean depending on the particular levels of measurement).

A similar process was applied to variables relating to the use of computers, the Internet and Internet-based communication.

Bivariate analysis

The next stage was to examine the data for possible relationships between variables.

Analysis was carried out around eight questions:

Who are the users of computers, the Internet, Internet-based communication and online groups?

- Relationships between status as a user/non-user of these aspects of the technology and personal demographic characteristics

How does computer/Internet/Internet-based communication use and online group participation relate to social involvement?

- Relationships between level of offline contact with friends and:
    - status as user/non-user of computers/Internet/Internet-based communication/online groups
    - time spent on computers/Internet/Internet-based communication
    - frequency of use of various types of Internet-based communication

What are the possible factors influencing people's satisfaction with their level of computer/Internet use?

- Relationships between how satisfied people were with their level of computer/Internet use and:
    - personal demographic factors
    - place of access to computers/Internet

How do communication preferences relate to personal characteristics?

- Relationships between personal demographic characteristics and level of preference for a particular communication medium (face-to-face, telephone, letter, email, live online chat, text messaging) when interacting a) with people who were friends and b) those who were not friends

How do communication preferences relate to level of offline contact with friends?

- Relationships between level of offline contact with friends and level of preference for a particular communication medium when interacting a) with people who were friends and b) those who were not friends

How do communication preferences and behaviours relate to each other?

- Relationships between respondent status as a participant/non-participant in online groups, and level of preference for a particular communication medium when interacting a) with people who were friends and b) those who were not friends
- Relationships between types of communication media in terms of respondents' level of preference
- Relationship between how much people would miss communicating over the Internet and how often they use different functions and types of online communication.

How do reasons for being involved in online groups relate to other personal factors?

- Relationships between reason for online group involvement and personal demographic characteristics and level of offline contact with friends

How does level of offline contact with friends relate to other personal characteristics?

- Relationships between level of offline contact with friends and other personal demographic characteristics

Measures of association

Cross tabulations were generated for the chosen variables in each case, and also measures of association depending on the level of measurement involved and the size of the table (see Table 2).

Level of measurement	Table size	Measure used
Nominal and nominal	2 X 2	Chi square, or Fisher's exact test when expected cell counts were too low
Nominal/ordinal and ordinal	Relatively few categories	Chi square
Ordinal and ordinal	Any size	Spearman's rho

Table 2. Measures of association

Collapsing categories

In some instances categories of ordinal variables were merged to generate a smaller number of categories with higher frequency counts thus facilitating reliable and interpretable analysis. Categories were combined in such a way that the continuum of ordinal variables was maintained.

The qualitative study

A methodology based on grounded theory

This study does not claim to use a pure form of grounded theory in its approach to the collection and analysis of data. Indeed many authors point out that it is rare to find instances of its uncontaminated application in the literature despite the claims of researchers (Bryman, 1988); others point out that even Glaser

and Strauss who originated the method disagree as to the precise constituents of a grounded theoretical approach (Charmaz, 2000). This method was chosen because it offers principles and techniques compliant with the epistemological and ontological stance taken, and which can guide the process of interpretation.

Grounded theory was developed by Glaser and Strauss in the 1960s in response to "an overemphasis in current sociology on the verification of theory and a resultant de-emphasis on the prior step of discovering what concepts and hypotheses are relevant to the area one wishes to research" (Murphy et al., 1998, p140). They objected to the data reductionism of quantitative data analysis in which data are fitted in to predefined categories and unanticipated emerging instances and ideas are neglected. The development of grounded theory was also a response to criticisms of qualitative analysis as unsystematic and impressionistic. As Charmaz (1995, p29) says "They articulated explicit analytic procedures and research strategies that previously had remained implicit among qualitative researchers".

Glaser and Strauss drew on symbolic interactionism as the basis of grounded theory, taking the view that meaning is created through interaction between people (Morse & Richards, 2002). The approach however also takes a positivist view of an external reality which can be discovered and is thus compatible with subtle realism. As such it is the interactions of the researcher which are instrumental in discovering reality. Through rigorous and systematic exploration, and with sufficient theoretical sensitivity the researcher can construct theory which is *grounded* in data. I shall now describe the principles of grounded theory and how they have informed the design of this study.

Data driven rather than hypothesis led

According to Strauss and Corbin "a grounded theory is one which is inductively derived from the study of the phenomena it represents" (Murphy et al., 1998, p140). It is therefore concerned with the generation of categories and theory which emerge from the data through a process of inductive reasoning, rather than the verification of pre-conceived hypotheses and concepts. Consistent with this, it was argued that the reviewing of research literature should not precede the collection of data, and that the coding of data should be based on emergent categories rather than a predetermined scheme. This study is an exploratory one and does not base itself on a formal hypothesis as such. However as Bulmer (1979, see Bryman, 2001) points out it is questionable as to whether it is realistic for researchers to suspend their awareness of relevant theories and

concepts until the late stages of analysis. Further, it would be difficult to initiate and design a research project without some prior knowledge of the subject area. As Bryman (2001) points out it could be argued that being aware of existing conceptualisations enables researchers to focus their investigations and build on the work of others. Although a comprehensive search did not precede data collection for this study, there had been some examination of relevant literature. The literature search continued as the interviews proceeded and fed into the iterative process of analysis (see below). In addition the survey had also raised issues which were taken into consideration during the interviews. Charmaz (1995) argues that such guiding interests and disciplinary perspectives, rather than limiting the investigation, provide *points of departure* from which to look at data, listen to interviewees and think analytically about the data.

An iterative approach

Describing the method of grounded theory Strauss and Corbin (see Bryman, 2001, p390) advocate that "data collection, analysis and eventual theory stand in close relationship to one another". Therefore in contrast to quantitative research where data analysis is generally seen as a separate phase of the research process, occurring after data have been collected, the approach in grounded theory is iterative, data collection and analysis occurring in tandem, repeatedly referring back to each other as description, concepts and theory develop and are refined. The role of the researcher and his/her *theoretical sensitivity* (Morse & Richards, 2002, p55) is integral to this process; by remaining "close to the data" (or as Maykut and Morehouse (1994, p123) put it " indwelling") data analysis is strengthened. However Maykut and Morehouse (1994) identify the paradox facing researchers who must at the same time be aware of how their own biases and assumptions may influence the process. Although theoretical sensitivity develops through interaction with the data, it also inevitably draws on knowledge of the literature, as well as professional and personal experience (Murphy et al., 1998).

The interplay between data collection and analysis is also crucial if, as recommended by Murphy and Dingwall (2003), contradictory evidence and negative cases are to be addressed rather than ignored in the generation of concepts and theory, hence strengthening validity and generalisability.

As well as occurring concurrently, two other elements of grounded theory contribute to the close relationship between data collection, analysis and theory

development. These are the *constant comparative method* and *theoretical sampling,* both of which enhance methodological rigour as well as generalisability based on theoretical inference (see earlier section: "Generalisability and validity").

When analysing data using the constant comparative method, "incidents" are compared with each other in order to derive concepts which capture their analytically relevant properties (Ten Have, 2004). As more data are collected, and comparison between incidents and concepts continues, new concepts may be added or existing ones modified, or indeed may merge into higher level categories, the integration of which may provide the basis of theory. This should continue until the concepts do not change through new comparisons, at which point they are said to be saturated.

As this procedure progresses, the selection of cases for further data collection is made on the basis of emerging concepts and theory so that further clarification and development may occur. This is known as theoretical sampling.

In terms of the iterative aspects of grounded theory, the current study incorporated a process of simultaneous data collection and analysis, the interview guide being amended throughout the process in the light of analysis of incoming data. The use of email as an interview format accommodated this aspect of grounded theory well, as I shall discuss later. As the researcher, I endeavoured to remain close to the data and use the constant comparison method as the basis of data analysis.

Although the sampling strategy was not theoretical as such, it was initially purposive, aiming for a diverse range of participants in terms of various aspects of Internet behaviour, as well as personal characteristics, to produce richness of data and emerging concepts. This involved approaching non or reluctant users of the Internet who were sent a series of open questions by post, as well as follow up questions based on their replies to the previous questions.

In the course of collecting data, further sampling was shaped by incoming data and analysis when it seemed that there was a general dislike of synchronous forms of Internet communication in comparison to the acceptance of email and also that there was a lack of representation of younger Internet users in the sample which could be a relevant factor.

Choice of data collection method

Semi structured interviewing

As an initial exploration of this research area, in depth interviewing was selected as the preferred approach to data collection. This method avoids the imposition of a predefined structure on informants, based on the researcher's own assumptions. In doing so the research is at less risk of failure to detect variations and nuances beyond a predetermined scope, and should enable the relevant issues to emerge and yield depth of information, which is of particular salience to this study where there was little prior knowledge of the research topic (Murphy & Dingwall, 2003). As Chen and Hinton (1999) point out, "interviewing provides the researcher with flexibility in data gathering, the ability to adjust ….to meet their needs and to probe areas….that may arise during a discussion". Ten Have (2004, p83) emphasises the interaction between researcher and participant, describing it as "a dynamically negotiated telling". The exchange between researcher and participant allows for rephrasing and clarification, an important aspect of achieving validity of data. This feature is also particularly pertinent in situations such as this study which involved dialogue between different cultures and communicative styles.

Whilst recognising the value of unstructured interviews which allow the participant to steer the focus of discussion minimising the influence of the researcher's own agenda, a semi-structured interview was used for the purposes of this study. It was guided by a protocol of pertinent topics, whilst being sufficiently flexible in terms of the content, wording and order of questions, thus allowing the participant more freedom in how they told their story and permitting unanticipated themes to emerge, be discussed and noted for inclusion in subsequent interviews. The element of structure was also predicted to be more comfortable for autistic people in terms of communicative style. The "use of an interview guide which provides structure and also permits deeper enquiry" has been recommended by Egan et al (2006, p1292) as a guideline for email facilitated qualitative interviewing with "vulnerable groups."

Research interviews however are criticised by many who see participant observation as the preferred method of data collection (Dingwall, 1997a). Becker and Geer (1960, see Murphy et al., 1998) argued that there is a greater reliance on the researcher's skills of inference and assumption in an interview situation, with the risk of misinterpretation and inaccuracy. There is also the risk of incomplete or inaccurate data from interviewees who may be unwilling or unable to provide all information, or whose perspectives or memory limitations

may affect their reporting of an event. Trow (1969, see Murphy et al., 1998, p119) however counters Becker and Geer's claims, arguing that the method of investigation is determined by the research question , and as such interviews are more suited for gathering information which is more attitudinal in nature, as is the case in the current study. Some criticisms of interview data relate to the lack of naturalistic context (Murphy et al., 1998, p119), something which is perhaps less of an issue in this study in which the topic of interview (online communication) is also the communication medium by which the interviews were carried out. This factor may also partially obviate for the criticisms of incomplete or inaccurate data. Silverman (1985, see Murphy et al., 1998, p119), warns that it is not the method of data collection which can claim superiority; what is of paramount importance is the method by which it is analysed.

It is important to discuss the role of other methods which could contribute to a study of this area. Many studies of CMC and CMSS have analysed discussions from Internet forums (for example Muncer et al., 2000; Pleace et al., 2000; Sharf, 1997). This strategy can yield a readily available archive of transcribed naturalistic discourse, a record of the phenomenon under scrutiny. However, due to the lack of definition between public and private spaces on the Internet, such research raises various ethical concerns relating to privacy, confidentiality, informed consent and ownership of narrative (for further discussion see Eysanbach & Till, 2001; Frankel & Siang, 1999; Sharf, 1999). In light of such issues Bowker and Tuffin (2004), in their exploration of online experiences of people with disabilities, opted for online interviewing as an alternative method of data collection. Similarly, given the current study was the first step into a new and potentially sensitive research area, naturalistic online data collection was contraindicated, although was recognised as a useful strategy for the future once the research is more established.

Pacagnella (1997) adds further caution to the use of analysing archived messages and logs, by noting the absence of information regarding the context of participants at their keyboards within their particular physical environments. Reid (1995, cited Pacagnella, 1997) comments also that CMC loses part of its sense and meaning when re-read afterwards by neutral observers. Commenting on their own research, Pleace et al (2000) felt that, without the support of interviews, discourse analysis was limited in its ability to identify the effects of online support on participants' lives. There is no doubt that the discourse from online forums would be a valuable aspect of this research topic to explore,

however its investigation would be addressing different issues rather than inviting participant perspectives as set out in the research question. Additionally it would be narrowing down the phenomenon of online communication to one specific aspect at an early stage of investigation into an under-researched topic, thus affecting the balance between breadth and depth of knowledge which is aimed for.

Whilst the "gold standard" of participant observation of online communities aims to reveal their true nature in depth and context and could be used to complement other methods, it prompts the same ethical questions and limitations as discourse analysis of online forums. Covert participant observation (such as that carried out by Pleace et al., 2000, in their study of an IRC room consisting of problem drinkers) brings extra ethical dilemmas whilst an overt approach (see for example Sharf, 1997) can risk expulsion of the researcher from the group, or invalidation of the study due to modified group behaviour. Reid (1996) warns of the detrimental effects of online data gathering on the supportive functioning of online groups. In her study there was a very positive response from the forum participants involved, indeed they were so keen to disclose personal information that some would only agree to being quoted on the condition that their email address and real name were cited also. However the researcher made the decision not to quote under these circumstances, which she considered may have been related to the disinhibiting effect of CMC. This turned out to be a wise decision, although the group did suffer a crisis following publication. The forum became the subject of a considerable level of public scrutiny and attention from other interested researchers, to the detriment of feelings of safety, privacy and trust.

Email as the interview format

Consistent with the observation by Witmer et al (1999, p146) that "on-line research demands methods…..specific to the medium", interviews for this study were conducted by email. Whilst there are several practical and methodological reasons for choosing this format, it cannot be viewed as an unequivocal substitute for face-to-face interviewing and hence its use raises methodological and epistemological questions which affect procedural and analytical aspects of the study design.

Implications of a physically absent researcher

An acceptable and egalitarian mode of interview for research participants?

A major justification for interviewing by email was the finding from the survey that this was the most widely acceptable way of communicating both with friends and non-friends for this sample, with presumed benefits in terms of participant recruitment and retention.

Mann and Stewart (2000) argue that to some socially marginalised people, the Internet can provide a safe and familiar environment in which to communicate, and as such affords a research medium in which their voices may be heard. There are examples of the use of online interviewing as a means of accessing the views of "hidden populations." Bowker and Tuffin (2003; 2004) interviewed people with disabilities online, and highlighted the potentially destigmatising effect of visual anonymity in CMC, as well as the provision of a physically safe and accessible location. Scott (2004) found that shy people became vocal, opinionated participants in online focus groups. Email interviews conducted with survivors of traumatic brain injury yielded rich data conveying humour and insight which challenged stereotypes of the social communication style of this group (Egan et al., 2006). Similar to these studies, and with particular parallels to research with shy individuals or traumatic brain injury survivors, this project aims to eliminate those aspects of the social environment which would impede interview interaction.

Citing various studies including their own, Mann and Stewart (2000) discuss the potential advantages of email as an interview format to participants more broadly. For those people with access to and experience of the technology, it afforded more choice over the timing and convenience of location for interaction. Email enables participants to answer at times convenient for them and allows the interview to occur in segments, thereby reducing the impact of tedium, fatigue and interfering distractions (McCoyd & Kerson, 2006). Participants are also afforded the advantage and comfort of being interviewed in a familiar setting, conducive to their needs (Bowker & Tuffin, 2004) with possible additional benefits for people with HFA/ASD given a tendency to prefer sameness of environment and routine.

Additionally, the Internet could be seen as a more neutral territory, one which breaks down the barriers between researcher and interviewee, autistic and neurotypical, allowing more fluent communication (see Mann & Stewart, 2000,

chapter 9 for more discussion of researching unfamiliar cultures), and possibly a more egalitarian interaction in which participants may feel empowered and more involved in the research process (Murray & Sixsmith, 1998). Chen and Hinton (1999) suggest that in the absence of a physically present interviewer, participants interviewed online felt that they had some control over the process, some feeling less nervous talking to a computer. Bowker and Tuffin (2004) highlight the potentially empowering effect of online interviewing to the interviewee who has more control over when, where and how they respond. Certainly the feedback from several of the participants in this study suggests a shift in perceived interview control that as illustrated by the quote below:

> *"I think that, had the interview been carried out face to face, the answers that you received would have been less considered; by answering in writing I had time to think about the matter before replying. On the other hand in a face-to-face interview you would have had more control and would have been able to prevent me from exploring ideas that interest me but were not strictly relevant to the question being asked."*

Conversely, Madge et al (2004) dispute this, pointing out that the power hierarchy persists online such that the researcher sets agendas, asks questions and is the beneficiary of the interview process. However with regard to this study involving people with ASD, the removal of the problematical aspects of face-to-face communication should have an equalising effect on the interview interaction.

An intimate interview situation conducive to self-disclosure?

According to theories and research discussed in Chapter 3, the lack of social cues and relative anonymity of CMC, may engender participants to be disinhibited in their online behaviour, and more open in their conversations, often with complete strangers, than they would be in an offline situation. With regard to the interview situation, online communication may ameliorate embarrassment or self-consciousness when discussing sensitive or stigmatising issues (McCoyd & Kerson, 2006). Seymour (2001, p163) points out that online interviewing may encourage more expansive dialogue due to the lack of bodily presence of research participants or a questionnaire acting as "a salutary reminder of the purpose of the research enterprise – data collection – not conversation or therapy." (The ethical implications of this issue will be explored later, see "Ethical issues.") Convenience of timing and location can also offer

more privacy, than say a face-to-face interview at home, and this may allow more candour and self-expression (McCoyd & Kerson, 2006).

Also, as discussed in Chapter 3, Walther (1996) claims that due to the reduction of social cues online, as well as the different pace of communication, CMC may be hyperpersonal, which may benefit the quality of interview interactions and encourage self-disclosure.

Although research evidence indicates that online communication can be more candid than offline situations, Hine (2005) points out the tendency to online disclosure is not guaranteed in online research, suggesting that it is sensitive to how researchers present themselves and their projects. Additionally for this project where the research participants experience face-to-face communication, empathy and social interaction differently, we can only reflect on how online communication may affect self-disclosure (and indeed this issue relates to the reason for the research itself). On the one hand interviewees may feel even less constrained by the lack of a physically present interviewer and the associated difficulties with face-to-face interaction with the effect of freeing them up to "be themselves" resulting in a tendency toward self-disclosure. Conversely, difficulties with empathy may render any difference between online and offline as unlikely if a lack of awareness of the feelings and perspective of others pervades both situations. As well as this it must be remembered that autistic disorders fall on a spectrum, individuals varying in the degree and nature of presentation of the core characteristics.

A medium for participant observation as well as interviewing?

Contemplation of issues of online communication for this group of people serves to raise methodological issues, and also to reflect on the research question and aims, and in doing so another benefit of conducting the research online becomes apparent; that is an element of participant observation was introduced to the study, so that I was able to experience Internet-based communication with people who have AS/HFA. As well as that it seemed to facilitate consideration on the research topic; there were certainly times when I found it easier to reflect on online interaction whilst involved in that form of communication and there were instances when this appeared to be the case for some of the participants also as the following excerpts illustrate:

> "*Re interference - depends what I'm doing - at the moment listening to music at work while writing this, as this conversation is not very exacting the music stays on.*"

">Webcams and video links…

With you a video link might add to the 'relationship'. Do you have a mental picture of what I look like? It is probably wrong."

"I'm only able to maintain the exchange however because you are leading it, given a specific task, however complex, I have the imagination and the ingenuity to work out a solution, but a question like "what shall we donext?" would probably leave me completely lost."

As Bowker and Tuffin (2004, p233) observed in their study: "Interviewing online also meant participants were more integrally engaged with the environment where the topic of the interviews was located, enabling more immediate engagement with the topic of discussion" (see also Bowker and Tuffin, 2003).

Can an interview take place online?

If the research was to take place by email, then consideration had to be given as to how the salient aspects of qualitative interviews would transfer to this medium and the impact on the data collected. Of particular relevance are the issues of rapport, flow, interpretation and richness of data.

Rapport in online interviews

Online communication does not yield nonverbal data, the paralinguistic cues such as facial expression, tone of voice, gestures which support verbal communication and help to establish rapport, add nuance to verbal meaning and facilitate conversational interaction as well as giving an indication of emotional responses. However as Lea and Spears (1995) contend, most suppositions on which theories of personal interaction are based, predate CMC thereby limiting their application to Internet-based communication. As we have already discussed, despite its leanness as a communication medium, warm relationships can and do develop online (Walther, 1992) ones in which some people seem more apt to disclose personal information about themselves than in offline situations. As has also previously been discussed, the participants in this study encounter problems using and interpreting nonverbal communication, and so the research interviews may not be compromised by the "stripped" nature of the online communication medium.

Two features of this study should compensate for any potential difficulties in the establishment of rapport between researcher and participant. Mann and Stewart (2000; 2001) cite several studies (for example O'Connor & Madge, 2001) in

addition to their own, in which the focus of research engendered enthusiasm from research participants, which enhanced the establishment of a comfortable online research relationship. Circumstances in which there was a sense of a shared research agenda and/or being given a space for their voice to be heard seemed to facilitate this process. The current study is based on such a topic. The other pertinent feature of this study is that it is based on asynchronous communication, which affords time and repetition of interaction in which rapport can develop (Kivits, 2005; Mann & Stewart, 2000; 2001; Murray & Sixsmith, 1998).

Fluency and momentum when interviewing online

One of the researchers contacted by Mann and Stewart (2000, p127; 2001, p613) found that "the lack of tone or gesture and the length of time between exchanges… can lead to something of a formal structured interview". This could impact on what Kvale (1996, p189) describes as "on-the-line interpretation", a valuable cyclical process of qualitative interviews in which interviewees describe their lived world and in doing so discover for themselves new meanings in what they experience and do. As this occurs in the course of the interview, the interviewer condenses and interprets the meaning and "sends" it back for further discussion involving confirmation or contradiction of the proposed construction. The lack of nonverbal interaction as well as the asynchronous nature of email may also create problems maintaining the momentum of the interview, or encouraging participants to elaborate on their answers, with the risk of participant drop out, or paucity of data. Once again it is worth highlighting that these issues may have different significance to the group of people in the current study.

Because of the potential difficulties affecting the fluency of dialogue in an email interview, practical measures were incorporated in to the study design to compensate for these issues (the maintenance of ongoing records of interactions and reflections for each participant, and attention to the speed and rate at which follow up questions were sent. See "Procedure" for more details).

Interpreting meaning online

The lack of nonverbal communication online has implications for the interpretive process in the sense of an interactive skill as well as an analytic one. In her study of young adults with common mental health problems, Shepherd (2003) found that in the course of email interviewing there were instances when she had missed or misinterpreted the emotional status of participants. This has

particular relevance when issues of a sensitive nature are involved and require careful handling (see "Ethical Issues" for further details). The benefit, however, of email interviewing when sensitive subjects are involved, is the time afforded to the researcher who can plan and revise with care the content and wording of questions and probes (Mann & Stewart, 2001, p618). Time to choose one's words carefully was also of value in this project involving a neurotypical researcher whose communicative style differed from those of the participants.

The loss of paralinguistic information from online interviews also affects the process of analysis, which is based solely on textual data. However the significance of such information in qualitative interviews is debatable. Chen and Hinton (1999) point out that the extent to which this information is included in the transcripts of face-to-face interviews is highly variable. Furthermore, according to Mann and Stewart (2000, p193), "translation of data involves making assessments of participants' mood or intentions which may well be incorrect." This is something which is even more likely to occur in the current study where researcher and participants differ in their use of nonverbal communication. McCoyd and Kerson (2006) note that from both ethnomethodological and feminist viewpoints there should be less interpretation on the part of researchers; respondents should be trusted to inform the researcher of their experiences from their own perspective. Indeed, the lack of nonverbal cues characteristic of email resulted in interviewees in their study using more explicit expressions of their feelings, such as parentheses (for example "crying now") or emoticons (McCoyd and Kerson, 2006).

A source of rich data?

According to Bampton and Cowton (2002) "the dislocation of interviewer and interviewee in an e-interview reduces the richness of messages that pass between them". However, as already discussed, there is evidence that it affords a space in which people may be more likely to open up and reflect on their inner thoughts, than would be the case offline. Shepherd (2003) and Egan et al (2006) commented that some interviewees seemed to value being able to use the email interview process for personal reflection and exploration. Shepherd attributes this to the lack of time pressure, and indeed found that it was difficult to achieve the same depth and richness of data during online chat interviews. The function of the online interviews as an opportunity for personal reflection was also evident in the feedback from some of the participants in the current study, for example:

"by having this online communication I am able to discover more about my own feelings towards Internet Communication methods."

"I thoroughly enjoyed the whole process and, as I stated above, have learned some things about myself."

As already mentioned, online interviewing enables participants to be interviewed in a familiar environment, a strategy proposed by Hammersley and Atkinson (1995) as preferable, one which may enhance self-disclosure and the richness of resulting data.

Additionally Seymour (2001), McCoyd and Kerson (2006) and Kivits (2005) regard the repetitive and longitudinal nature of the asynchronous online interview as conducive to rich dialogue, with the potential for rapport to develop, and for the ongoing complexities of human life to emerge over an extended time frame. As one of the interviewees in this project said "It also meant that the interview covered my use of the Internet over a period of time whereas a face-to-face interview would have been dominated by what I was doing on the Internet at the time of the interview."

Kivits (2005) also values the facility to re-read the ongoing interview text as a valuable contribution to reflective interaction and depth of data yielded. Some commentators (see Holge-Hazelton, 2002; Mann & Stewart, 2000) argue that email produces data which combine the interpersonal nature of face-to-face interaction, with the expansive reflection of writing, making it an excellent tool for qualitative research. The value of using online communication to interview people in this study is that the mode of interviewing is also the topic which may add to the potential depth of reflection and expression.

Bowker and Tuffin (2004) discuss the implications of ambiguity and misinterpretation in online interviews arising from the absence of nonverbal or paralinguistic cues, something which Hamman (1997) experienced in the course of synchronous online interviews. In their study Bowker and Tuffin included additional information and questions for the purposes of clarification, but in so doing this would narrow participants' interpretation and constrain responses. This resulted in the researcher negotiating "a fine line between insufficient information and information overload" (Hamman, 1997, p237)

Chen and Hinton (1999), discuss the issue of spontaneity of responses in email interviews where it is not known how much editing has occurred before posting. Participants can therefore be more measured in their responses than in face-to-face interviews changing the nature of the data produced. However Crystal

(2001) suggests that email seems to be a somewhat more spontaneous form of communication, than conventional mail for example, being characterised by a greater degree of spelling and grammatical errors, as well as unconventional phrasing. As I shall explore in more depth later (see "Status of interview data"), it is of more importance to take this electronic context into consideration as part of data analysis rather than seeing it as a source of invalidity.

Because of its long term nature, the choice of email as an interview format bestows flexibility with potential benefits for the depth of data collected. McCoyd and Kerson (2006, p401) point out that "email interviews allow follow up questions in ways that face-to-face interviews do not". The use of email expands the possibility of incorporating new topics into the guide, in response to the emerging data and its analysis, consistent with a grounded theory approach. This may occur within the same ongoing interview with a participant, or there may be cross-fertilisation between ongoing interviews with different participants (Bampton & Cowton, 2002; Murray & Sixsmith, 1998). I would also suggest that the ongoing nature of the email interview supports the researcher in the process of becoming close to the data during collection and analysis, thereby strengthening the iterative process and enhancing richness and depth of data.

As can be seen from the discussion so far, there are many ways in which email has been proposed as a tool by which rich interview data may be obtained. Although its use in qualitative research is increasing there has been little methodological analysis of this medium. In their study McCoyd and Kerson (2006) were able to compare email interviewing with telephone and face-to-face interviewing with the same study population (women experiencing grief after terminating a desired pregnancy due to diagnosis of foetal abnormality) and using the same interview guide. Email produced the longest interviews, in terms of interview transcript, and yielded data of a richness comparable to face-to-face interviews and superior to those conducted by telephone. They found that "many respondents wrote in a stream-of-conscious manner, which seemed to enhance credibility…" (McCoyd & Kerson, 2006, p397).

What is truth online?

According to Seymour (2001), the body has traditionally been regarded as central to qualitative research, which raises questions of the veracity of online data. Sensory and motor skills are tacitly involved in the interaction between researcher and participant in constructing knowledge. However Seymour warns

that despite feeling comfortable and confident about their person-to-person skills, researchers may fail to analyse their assumptions about such interactions, and she therefore debates whether online research methods may in fact afford some protection from such unscheduled agendas, raising the possibility that online communication may mediate between the qualitative-quantitative dichotomy: it has the potential to yield rich, reflective data from participants whilst removing some of the complicating nonverbal aspects of interaction. If knowledge of the world is, as Campbell (1994, see Murphy & Dingwall, 2003, p13) suggested, influenced by "the cultural-biological lenses through which it is seen" then textual interaction will be viewed through an essentially different lens. The issue is whether the stripped nature of the communication is such that it can be seen as a purer form of communication, less distorted as it were by the nonverbal aspects of interaction, and therefore a "truer" representation of reality. We should however remember that text functions as a representation. Seymour concludes, simply that our confidence in the truthfulness of data should be no different online to offline.

Consideration of issues of truth or reality raises the question of whether cyberspace represents a distinct reality, or whether, as Orgad (2005) proposes, it cannot be separated from its social framework and as such online research suffers from a "lack of ethnographic context" (Pacagnella, 1997). Orgad does not imply that data obtained by online methods are less authentic than other types of data. However it should be interpreted and judged in the context of its production. Murray and Sixsmith (1998) suggest that responses may be affected by the cultural context, as well as extraneous distracting factors, in which informants access the online interview. We must therefore see the potential contrasts between a work/home environment and the private/public situation and recognise that knowledge of location is limited in an online interview context and that there is no single nor shared place of communication in which the interview takes place.

Practical benefits and challenges

As Chen and Hinton (1999) point out, computer-mediated communication enables inexpensive interviewing over long distances. Additionally in the case of email interviewing, the requirement of finding a mutually convenient location and time for interviewing is removed. This interview method also eliminates the need for transcription of data, with its potential for error and bias (Bampton & Cowton, 2002; Mann & Stewart, 2000) and reduces the challenges of data handling. Such benefits reduce time and money costs, with the potential to

conduct a wider range of interviews than may otherwise be possible. However the issue of time is complex. The nature of email interviews is such that, depending on the rate of exchange of messages, a potentially long timescale is involved, one which cannot be easily predicted with any accuracy (Bampton & Cowton, 2002). There is a risk that the lengthy duration of interviews impose more of a burden on the time and commitment of participants, who may struggle to sustain their interest and motivation in the project (Seymour, 2001). From the point of view of the researcher, the lack of temporal parameters and the close and simultaneous involvement in several individual's lives for extended periods of time is comparable to a participant observation study, with a similar requirement on energy to maintain an appropriate level of engagement, whilst avoiding burn out or "going native" (Egan et al., 2006; Seymour, 2001). The design of this study has taken into account the challenges presented by the prolonged nature of email interviews (see "Procedure" and "Ethical issues").

The anonymity of Internet communication raises difficulties verifying participant identity. As Madge et al (2004) point out this is not a problem which is unique to online methods. However the Internet is a medium in which people may feel freer to experiment with their identity or actively deceive those with whom they interact. This limitation must be acknowledged and data should be subject to rigorous analysis to minimise such an effect. The use of asynchronous rather than real time online interviewing may mitigate against active deception in the challenge it presents to the participant to maintain the dishonesty for a protracted length of time over a large number of exchanges.

The use of the Internet as a means of interviewing can be seen as inclusive, facilitating the involvement from those who may have been inhibited to take part due to disability, time constraints and/or language and communication differences. Whilst the potential for the inclusion for people with ASD in research has been highlighted, the exclusion of those who lack technological skill or access should be considered. To address this contributions were invited from those who were non or reluctant users of the Internet, elicited by means of a series of open ended questions sent by conventional mail (see Appendix H).

The potential for technical problems should be considered for example disappearing text and changes of email address. McCoyd and Kerson (2006) found that such instances were generally resolved without undue disruption.

Ethical issues

To address the ethical issues inherent in the project, careful consideration was given to the research topic, the needs of the participants and the method of data collection.

Of most concern was the issue of conducting research with a group of people whose social and communication difficulties create potential vulnerabilities and misunderstandings, particularly when the interview would inevitably address issues relating to those problems. The asynchronous text-based nature of interviewing involved, whilst allowing more time to consider how to deal with sensitive issues and creating a possibly more conducive communication situation for people with ASD, prevented me from obtaining any nonverbal feedback regarding participants' reactions, nor the location in which these would occur. Additionally, the long term period of contact involved in an email interview, as well as the potentially more intimate nature of online interaction, raised the possibility that some dependency may evolve in the course of interviewing. There was also the risk of "stranger on the train" phenomenon. Because the interviewer is not visible to the participant their awareness of the function of the interaction may waver, and they may be more apt to disclose information they would not otherwise have done in other more self-censored forms of communication (Hiltz & Turoff, 1978, p28; McCoyd & Kerson, 2006), which may include admissions of illegal activity by people who perceive the Internet as uncensored and unpoliced (Coomber, 1997, see Mann & Stewart, 2000, p54).

In response to the ethical concerns raised, the following actions and principles were implemented (some of which emerged with experience as the interviews progressed):

1) Informed consent was obtained from participants before proceeding with interviewing. They were directed to a website explaining the purpose of the study, the voluntary nature of participation, methods involved, dissemination of results, researcher's contact details, complaints procedure as well as their rights to privacy, confidentiality, withdrawal from the study, freedom to turn down questions they did not wish to answer, and security of data storage (see Appendix I). The project website also contained relevant background information about the researcher and her supervisor, a description and flowchart representation of the process involved in an email interview, and the broad topic guide (see Appendix J).

2) A protocol was established on the website process document to the effect that if an email from the researcher was not replied to after seven days, it would be resent in case it had not reached the participant (Bampton & Cowton, 2002). Along with its reissue, the researcher would however also enquire as to whether the informant wanted to cease participation in the project, or whether he/she had any concerns regarding the previous email or the project more broadly.

3) If in agreement, participants were asked to sign a digital consent form covering their rights to privacy, confidentiality, withdrawal from the study and security of data storage (see Appendix K).

4) Efforts were made to maintain participants' awareness of the research interview nature of the online interaction:

    i) The email address for interviews was separate to the researcher's personal university account, and had an impersonal username, "Internetproject"

    ii) A link to the project website was attached to the end of each email from the researcher

    iii) Emails were worded in a way as to remind informants that they were taking part in an interview for example "To continue with our interview…", "I would like to introduce the next topic from the guide on the website…", "For my next question…"

5) The researcher, in wording her emails, was aware of the communication needs of the research participants and gave careful consideration to minimise the risk of misunderstanding. She endeavoured to use clear, unambiguous language and frame emails in a structured manner, being vigilant for signs of misinterpretation and prepared to rephrase and clarify as necessary.

6) Careful consideration was given, when issues of a sensitive nature emerged in the course of interviewing, as to the wording and indeed appropriateness of further probing such matters.

7) As the project proceeded, there was a growing awareness of the potentially different nature of "social chitchat" online. A seemingly "throwaway" sociable remark could carry more weight due to its permanence, and the more intimate and long term nature of the interview interaction, possibly being seen as a sign of a stronger relationship to this group given their

social interaction problems and vulnerability. Again careful attention was paid to the social use of language, recognising this risk but at the same time acknowledging the value of such discourse in establishing rapport. Indeed several authors (Bowker & Tuffin, 2003; Joinson, 2005; Kivits, 2005; Mann & Stewart, 2000; 2001) highlight the value of sharing personal information as a means of opening up dialogue online and reducing the power differential between researcher and participant (Bowker & Tuffin, 2003). Orgad (2005) however in her research online maintained a certain distance, which was my approach to self-disclosure in this study. Despite suggestions in the literature (for example O'Connor & Madge, 2001; Ryen & Silverman, 2000) photographs of the researchers were not included in the project website.

8) Participants were alerted to the impending end of the interview in stages: last topic, closing question, closing email (in which they were thanked for their participation and told they would be contacted again to be sent a summary of results). This was a strategy also employed by Egan et al (2006).

In addition to these principles specifically orientated to this project, there was adherence to standards of confidentiality, privacy and data storage. Personal identifying information was kept separately from interview data and links between the two coded. Any paper documents were stored in locked cabinets at the University. Computer database files were password protected. In the writing of reports identities were anonymised at all levels (real names, user names, domain names), and care was taken to avoid the use of quotes that would comprise personal privacy.

The interview stage of the study was reviewed and approved by the University of Nottingham Medical School Ethics Committee (see Appendix L).

Sample

Participants for interview were selected from a substantial number of the survey respondents who had indicated an interest in taking part in the second stage of the project. A purposive approach to sampling was taken aiming to obtain a group reflecting diversity in terms of sex, age, employment status, residential status, level of autistic trait (as measured by the AQ), type of Internet communication used (chat and/or email), time since diagnosis, level of social contact, participation in online groups, country of residence, level of importance attached to Internet-mediated communication. Such an approach increases the

likelihood that variability common in any social phenomenon will be represented in the data (Maykut & Morehouse, 1994).

As explained previously (see "An iterative approach") further selection of participants was guided by concepts which emerged as incoming data were analysed.

Potential participants were approached by email to see if they were still interested in being interviewed and were directed to the project website for further information (see "Ethical Issues" for details). If they were agreeable with proceeding with their involvement informed consent was obtained, and participants were alerted to the fact that there may be a time delay (between one and six months) before interviewing began.

Interview guide

Drawing on issues which emerged from the survey findings as well as those gained from consulting the literature regarding ASD and CMC, an interview guide was generated. This was based around four broad topics, or Charmaz's "points of departure" (Charmaz, 1995), which were those available on the project website:

> **Topic 1**: Reasons for getting involved in online communication and its effect on your life
>
> **Topic 2**: The Internet as a communication medium and how it compares to other forms of communication e.g. face-to-face, telephone, letters, text
>
> **Topic 3**: Who do you communicate with online and how do these relationships compare to relationships with people in the real world?
>
> **Topic 4** What motivates you to be involved in an Internet-based group (e.g. chat room, bulletin board, newsgroup) or not?

A more detailed version was prepared which contained suggested probes (see Appendix M). Based on the principles of grounded theory, this guide was regarded as a flexible research instrument, such that unanticipated themes which emerged in the course of interviewing and ongoing analysis would be allowed to develop and could be incorporated into the topic guide.

Procedure

Interviews commenced with an introductory email in which the first broad topic was introduced and responses invited (see Appendix N). This email also aimed to reassure participants regarding the acceptability of their responses whatever their length and content, and explained the use of follow up questions to assist the flow of dialogue. These were felt to be important points to make given the open nature of interview questions being put to a group of people who may need some encouragement to broaden their answers. Also, as Scott (2004, p95) notes with regard to her interviews with shy people (face-to-face and online), in which similar reassurances were provided, it is important to "protect vulnerable participants from any unnecessary distress." Participants were also reminded about the project website and encouraged to look at it again before replying or at any time during the interview.

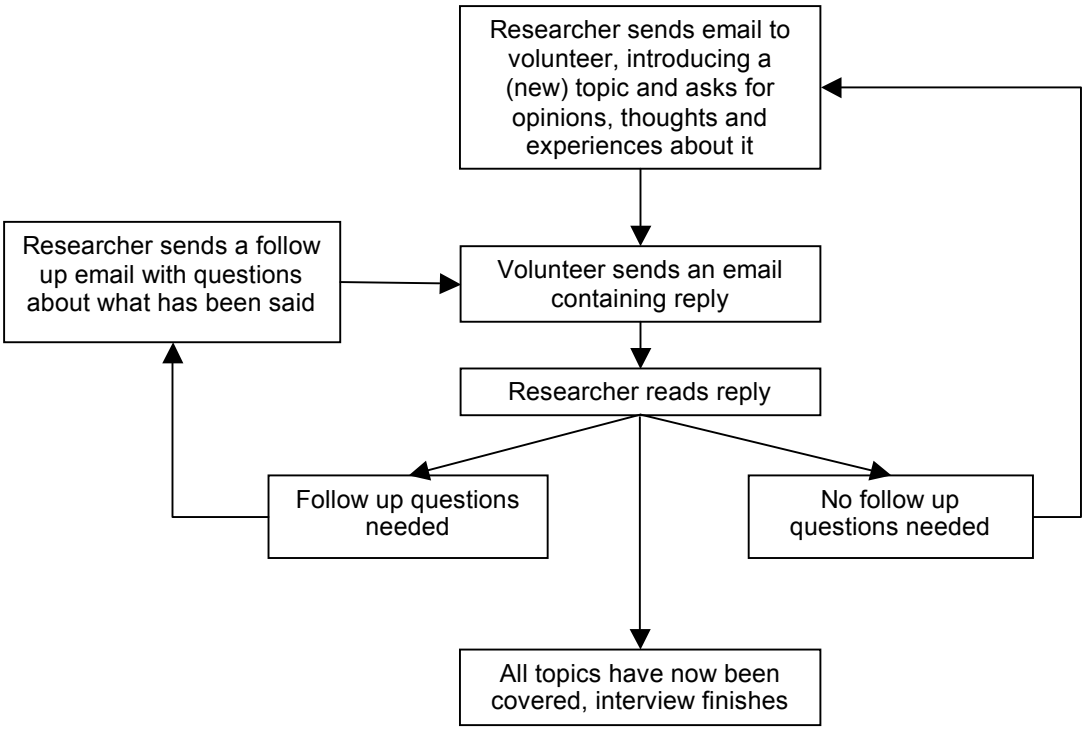


Figure 3. Flow chart guiding interview process

Figure 3 shows the flow chart contained on the website which guided the email interview process. Also contained on the website was the list of four broad interview topics. It was felt that this information should be available prior to and during the interview because the use of email is still relatively novel. Also by being alerted to what was involved, participants would be able to make some judgement about the commitment involved (Bampton & Cowton, 2002),

perhaps even approximately how long the interview might take, something which is hard to generalise about in view of differences in rate of exchange of emails, style of communication online and level of participant engagement with the topic. Mann and Stewart (2001) see the provision of a schedule ahead of the interview as beneficial to the establishment of trust and rapport online, whilst Egan et al (2006) included this aspect in their guidelines for email facilitated qualitative interviews. Additionally for this particular group of informants it was important to provide the supporting information given the difficulties dealing with change and also processing and retaining verbal information, characteristic of ASD.

As Kivits (2005, p35) remarks, the email interview involves "constant negotiation…. where motivations waver between establishing and keeping up an interpersonal and enjoyable talk with respondents and simultaneously installing a delineated research interview situation", skills which are more tacitly employed in the face-to-face situation. In the absence of nonverbal information the email interviewer more consciously develops and adapts interactive skills in response to the individual informant's style and needs, and benefits from time for reflection between interactions. I found that I developed a sense of how many follow up questions to send and how quickly to respond to individual informants' emails, in order to maintain interview momentum and fluency, whilst striving to avoid becoming a nuisance and overwhelming participants with my enthusiasm! (see also Bampton & Cowton, 2002.)

It was important to develop the skill of listening and reassuring through words rather than the nonverbal means associated with the face-to-face situation (Kivits, 2005; Mann & Stewart, 2000; McCoyd & Kerson, 2006). This involved expressing interest in replies received, emphasising the value of contributions being made, as well as being alert to changes in the online conversational tone for signs of reticence, disinterest or misunderstanding.

In order to manage several ongoing and simultaneously occurring interviews, each at its own individual stage, two Word documents were maintained for each participant: one in which each interview email was pasted and as such the interview grew; the other was a record of "ongoing thoughts", which included future lines of enquiry, potential concepts for analysis, and reminders for future emails. Examination of these documents and the interview guide as an email was received from a participant enabled me to reengage in and reflect on that particular interview before replying and continuing the dialogue. This system also encouraged more depth to the interview, enabling me to go back to points

at later stages in the interview, something which is limited in a person-to-person situation. In their study, Egan et al (2006) also found that re-reading of previous emails was a necessary if time-consuming practice.

Pilot

The first three interviews served as pilots, and participants were asked for their general feedback on the process, content and time commitment involved in the interview at two points during the interview, as well as their responses to a short questionnaire when the interview was complete (see Appendix O). As a result no changes were needed to the process as such, although the issue of open questions and their potentially daunting impact was raised, particularly with respect to the first opening topic question. Therefore reassurance was given when this question was sent in subsequent interviews, the researcher acknowledging that this may seem a huge, broad question, and reiterating the acceptability of answer of any length or substance which could serve as the basis for follow up questions in order to elicit further information. The issue of the rate of email exchange also emerged from the pilot feedback, as an aspect to be aware of in terms of the need for a pace which maintained momentum of the interview, without placing undue pressure on the particular informant.

Data analysis

The status of interview data

In approaching analysis it should be established what status is being attributed to the data under scrutiny. For this study this will depend on the perspective taken toward the purpose of the research interview, the roles of its participants and the mode of data collection.

Holstein and Gubrium (2004) describe the conventional approach to interviews in which the interviewee is regarded as a passive vessel of answers, not engaged in the production of knowledge but providing rational, factual information in response to questions. The product of such a model is a report on external reality, which is potentially true. The interviewee acts as a witness and provides information for a veridical reading, to investigate its validity (Kvale, 1996, p223).

Another model of the interviewee is that as informant of their internal reality; their own experiences, meanings and motivations pertaining to the subject under study. Thus interviews allow us to discover the "insider perspective", which could not be discovered through observation (Patton, 1980 see Murphy &

Dingwall, 2003, p93). This model also confers a relatively passive role for the interviewee, albeit the emphasis may be viewed as having deeper and more authentic value, the data obtained being subject to experiential interpretation to clarify the meanings and understandings of the participants (Kvale, 1996). Whyte, however raises the issue of ambivalence as a limitation of the role of the interviewee as providing an account of internal reality (see Silverman, 2001, p112): "…men can and do hold conflicting sentiments at any given time. Furthermore, men hold varying sentiments according to the situation in which they find themselves." To categorise accounts as either true or false would be to misrepresent them. However it could be posited that the long term nature of email interviewing would allow more time and opportunity for this ambivalence to be explored.

The conceptualisation of interviewee as passive derives from a realist position, linked to the positivist stance of a truth which may be discovered. The alternate paradigm, based on constructionism, would see the interviewee as an active participant in the interview. Kvale (1996) terms this an interrelational approach to the interpretation of interviews; the meanings belonging to neither party but existing between them, in their interaction. Dingwall (1997b) describes an interactional "dance of expectations" in which participants' actions are determined by how they expect others will perceive them. As such Goffman (1959) argues that interviews are instances for "impression management", both interviewee and interviewer, striving to present themselves, albeit subconsciously, in a culturally appropriate and acceptable way. As Mathieson and Stam (1995, see Murphy & Dingwall, 2003, p84) point out "these conversations are coloured by the position of patient versus researcher, narrator and listener, question and answer, yet the narrative is a combination of the intended and unintended consequences of the interaction."

Rather than a potentially true report on reality the interview is a display of moral or cultural forms (Murphy & Dingwall, 2003; Silverman, 2001). Instead of acting as witnesses, the interviewees are representatives, providing situated accounts, about the normative context in which they operate (Murphy & Dingwall, 2003). Interview data should therefore be subject to a symptomatical interpretation (Kvale, 1996).

Joinson (2005) discusses the impact of online formats on the potential for impression management. In theory the anonymity of the Internet would reduce socially desirable responses based on impression management, but would not affect the influence of self-deception on participants' discourse. Empirical

studies of this phenomenon (based largely on questionnaire studies) however have produced varying results: in some cases only impression management is affected but in others self-deception is also reduced. In some studies increasing the amount of control participants had over the process increased their tendency to impression manage (Fox and Schwartz, 2002, see Joinson, 2005). It could be argued that asynchronous interviews afford considerable control to research participants, permitting them the time to plan, check and edit messages and generate socially desirable responses.

My orientation toward the data collected for this study, is informed by the previously stated position of subtle realism. Rather than basing interpretation on a purely externalist or internalist stance, as either reports on reality *or* situated narratives, interview data were seen as providing potentially accurate descriptions of the occurrences they report. However as Murphy and Dingwall (2003) point out, all talk, including that which occurs in an interview, is socially and contextually constrained and as such accounts should not be taken at face value.

The issue is the function being fulfilled by the informant and interviewer through their talk (Silverman, 2001). An interview may be shaped by several functions in simultaneous and interacting operation. This may include providing an accurate account, but may also involve micropolitical projects or favourable self-presentation (Murphy & Dingwall, 2003). Therefore, in advocating a cautious approach to the analysis of interview data, Hammersley and Atkinson (1995, p126) urge the researcher to understand the context in which accounts are produced, to consider "the presuppositions on which it relies, who produced it, for whom and why". Holstein and Gubrium (2004) take a similar interactionist view of what they term the "active" interview and propose that meaning is constituted in the "hows" and the "whats" of interpretive practice, that is how informants construct aspects of experiential reality in collaboration with the interviewer. They cite Pool's metaphor of the interview as "an interpersonal drama with a developing plot" (see Holstein and Gubrium, p149) to convey the essence of the active interview. As such, analysis of data requires sensitivity to the interview process and the unfolding substance of responses.

Regarding the group of people who were interviewed for this study, it could be hypothesised that they may be less apt to construct acceptable responses for the purpose of "impression management" since autism is characterised by literal use of language and difficulties understanding the perspectives of others. Perhaps this group may be considered to be more concerned with providing an

accurate account, than in the case of other groups. The rigour of the constant comparison method, as well as the search for falsifying evidence, should also contribute to the evaluation of the trustworthiness of data.

The process

The approach taken to the analysis of a corpus of qualitative data can be placed along a continuum ranging from a low level of interpretation and abstraction to one of a high level of interpretation and abstraction consistent with the construction of theory (Strauss and Corbin, 1990, see Maykut & Morehouse, 1994; see also Murphy et al., 1998). Given the exploratory nature of this research the approach taken in this case was "interpretive-descriptive" (Belenky 1992, see Maykut & Morehouse, 1994, p122); that is the primary aim was to describe the phenomenon, whilst realising that some interpretation was inherent in the process of data analysis, and allowing for theory generation should the possibility become evident.

The main components employed in analysis of the data, which drew on a grounded theory approach, were coding, constant comparison, theoretical saturation, and memo writing.

Qualitative analysis entails the researcher becoming familiar with the data, in the course of both collection and analysis. As has already been discussed the prolonged nature of the interviews and contact with participants lent itself to close involvement with emerging data. In terms of the analytic procedure the first step should develop this familiarisation process further. Therefore time was given for close and repeated reading of the data, followed by an initial unitising, that is identifying chunks or units of meaning (Maykut & Morehouse, 1994) or incidents (Murphy et al., 1998) which could stand by themselves and which could serve as the basis of defining larger categories of meaning. The researcher and two health researchers, experienced in qualitative data analysis, applied this process to the first two transcripts and then met to discuss their analysis at this early stage. There were also further meetings to discuss the evolving theory and concepts, with reference to transcripts as the process continued.

This initial stage aimed for systematic line by line coding as recommended by Charmaz (1995) since it encourages the researcher to look at the data critically and analytically, in new ways which may differ from the interpretations of research participants. As this open coding (Murphy et al., 1998) proceeded on incoming data, similar incidents were grouped together to form concepts, which

were referred to as more incidents were identified and coded. With the coding of more data, and continued reflection, new concepts emerged, concepts became further elaborated, and in some cases merged to form higher level categories. This process of continued simultaneous reference between incidents, concepts and categories is known as the constant comparison method.

Coding became progressively more focussed and selective, that is those codes and concepts which continually reappeared through open coding and which were emerging as conceptually significant served as the frame of reference for further data analysis, although constant comparisons continued to be made. In this way the process was not a linear one, and reference back to the data, incidents, and concepts were made as appropriate.

Strauss and Corbin (1990, see Murphy & Dingwall, 2003) define coding as an operation which permeates the entire analytic process, one in which data are broken down, conceptualised and put back together again. Accordingly, as analysis proceeded and concepts emerged, the process of axial coding was adopted, in which possible connections between categories were explored, relating for example to contexts and consequences. Additionally as coding became more selective, certain categories surfaced as core to the emerging system of codes, categories around which others configured.

As well as interplay between the various levels of coding, there was also interaction between emergent categories and the data collection process in terms of topics and questions raised subsequently during interviews, and some sampling for contradictory cases or further illumination of existing categories.

This highly interactive analytic process continued until theoretical saturation had been achieved, that is when categories were well developed and did not change through new comparisons.

The process of coding and generation of concepts and categories was supported by the writing of memos, notes about the insights and ideas emergent during data collection and analysis, which were incorporated in to the iterative procedure, being revisited, compared, revised and developed in the light of incoming incidents, and evolving codes, concepts and categories.

Summary

This chapter has given a detailed account of the decisions made in devising this piece of research. The crucial points are that this study was based on an

approach of subtle realism, and combined qualitative and quantitative methods for the collection and analysis of data: a survey followed by in depth interviews. In this way the intention was for breadth as well as depth of knowledge. Survey respondents constituted a non-probability sample, due to the intrinsic challenges accessing this particular population (people over the age of sixteen who had Asperger syndrome or high-functioning autism). The survey provided contextual information pertaining to the respondents' use of Internet-based communication, and also raised issues to be followed up in more depth in the second part of the study, in which a subset of respondents were interviewed by email about their experiences, motivations and perceptions regarding the Internet as a communication medium. Data were also collected from four non or reluctant Internet users who responded to a series of open questions sent by post, as well as follow up questions based on their replies to the previous questions. With reference to the literature pertaining to the fields of autism, CMC and research methods, as well as my experiences of using email as a means of conducting interviews during this piece of research, I have discussed the epistemological, methodological and practical issues raised by the use of this relatively new interview format.

The findings of the survey are presented in Chapter 5 and their implications discussed in Chapter 6. The themes emergent from analysis of the interview data are presented in Chapter 7, and discussed in Chapter 8.

CHAPTER 5: SURVEY RESULTS

Introduction

This chapter presents the results of analysis of the survey data. As described in the "data analysis" section of Chapter 4, univariate analysis was carried out to obtain profiles of the personal and demographic characteristics of the sample, as well as patterns of use, access and motives regarding computers, the Internet and CMC, with reference also to other forms of social contact and communication. Also presented are significant relationships which were found between variables as a result of bivariate analysis. These associations elaborate the descriptive findings of univariate analysis, and inform the second stage of the study, in which a sub-sample of the respondents was interviewed in more depth about Internet-based communication.

When reading this account of the findings of analysis, it should be noted that the values for the totals quoted (n=) vary. This is partly due to some questions being ignored by respondents, even though they were presented to them. Mostly, however, it is due to the fact that there was progressive filtering of questions as respondents worked through the questionnaire, depending on their particular circumstances as reflected in their responses, thus not all questions were answered by the whole sample. This is illustrated in Figure 4.

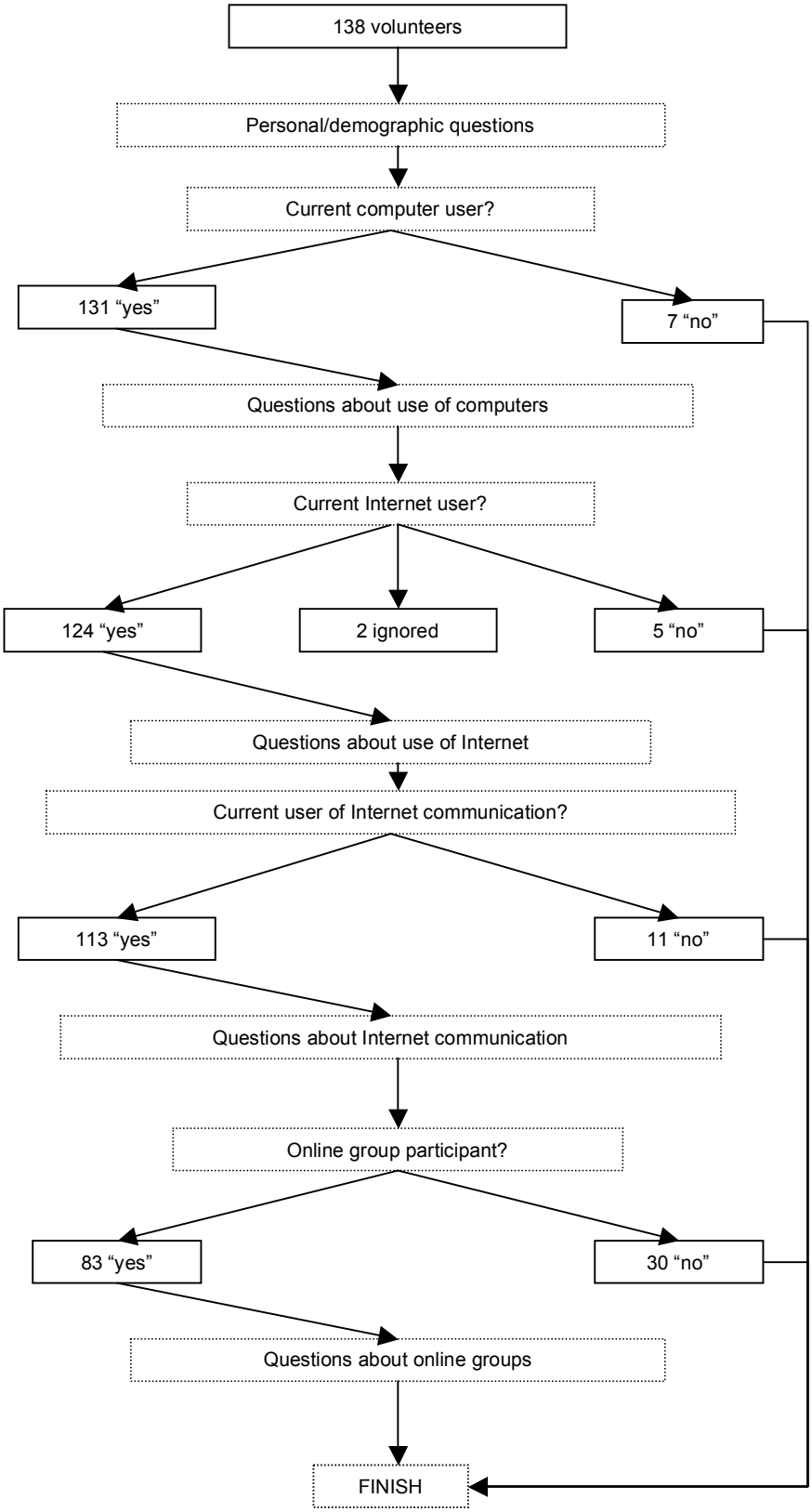


Figure 4. Filtering through the Internet Questionnaire

Characteristics of the sample

A total of 138 people completed the questionnaire. Of these 92 (67%) had completed postal questionnaires and 46 (33%) had completed the survey online. 61% of the sample had volunteered to participate in response to adverts, the rest were recruited via "gate keepers". 89% of the sample were resident in the UK. Other countries of residence were USA, France, Israel, Netherlands, Norway, Canada, Germany and Australia.

83 people (60% of the sample) agreed to complete the AQ. The mean AQ score was 35.3, with a standard deviation of 9.2. The interquartile range indicated that 50% of those tested scored between 29 and 43, with a median and mode of 37. Of those who completed the AQ, 81% obtained scores of 26 or above, the threshold suggested by Woodbury-Smith et al (2005) as indicative of clinically significant levels of autistic traits.

Figure 5 shows the distribution of the sample by age group. The modal value for this variable indicates that the age group into which most respondents fell was 20-29 years.

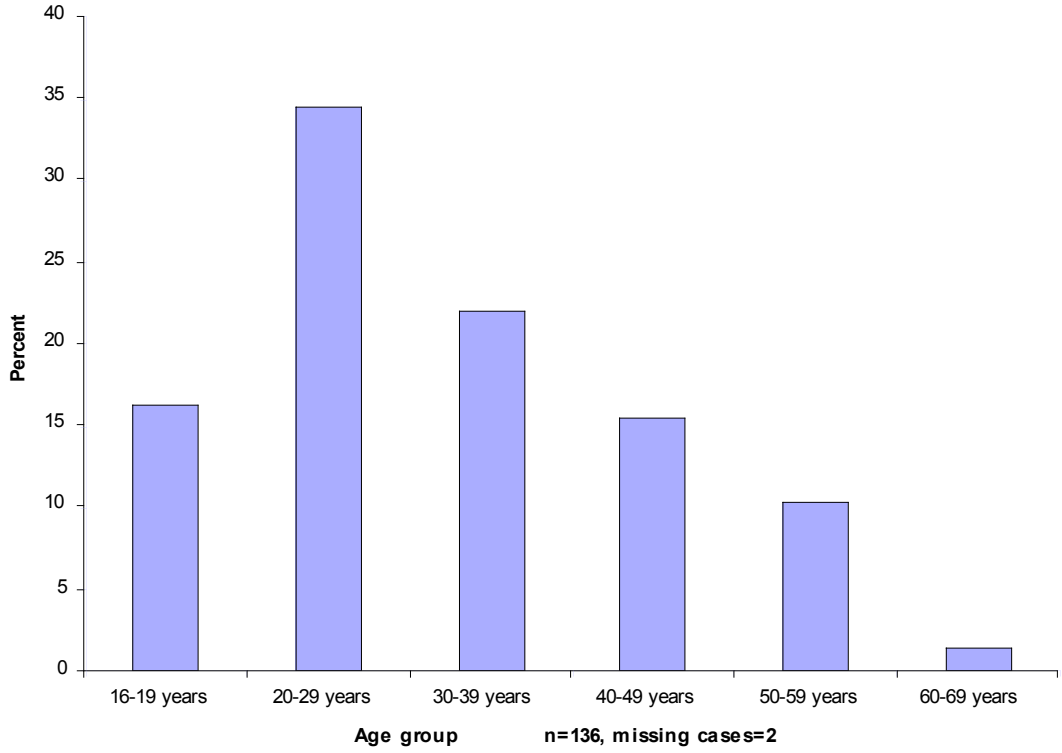


Figure 5. Age group distribution of the Internet Questionnaire respondents

Five respondents indicated they did not have an official diagnosis of ASD (although at least two were actively pursuing this, also four of them scored

over the discriminatory threshold score of 26 on the AQ) and one had a diagnosis of semantic pragmatic disorder. As shown in Figure 6 the typical age for diagnosis of ASD for this sample was 21 -30 years old.

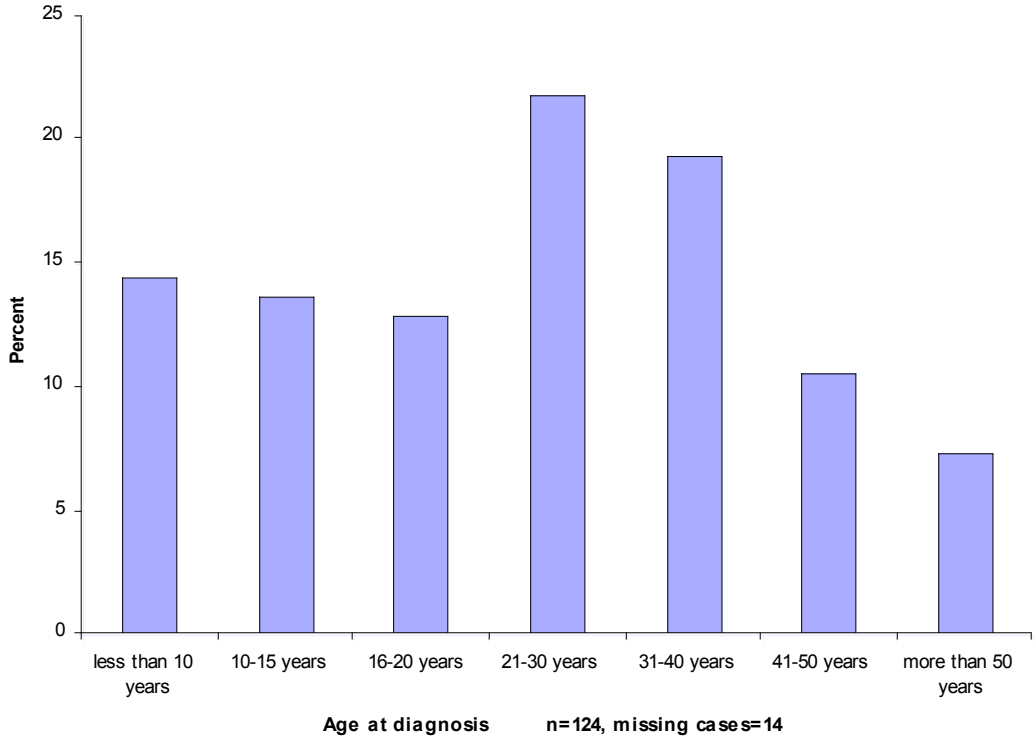


Figure 6. Distribution of age at diagnosis for survey respondents

In terms of gender the large majority of respondents (72%) were men (n=137). In terms of ethnicity, most respondents (85%) described themselves as white British (n=136). 6 people identified themselves as mixed race. There was one Chinese respondent. The rest (10%) responded as belonging to ethnic groups not specified as an option on the questionnaire.

28% of respondents were in full time education and a further 35% had a job (n=135). Of the 47 people in work, 46% were engaged in sheltered, supported or voluntary work, or a government training scheme.

Figure 7 shows the type of jobs held by those who were working based on the Standard Occupational Classification (Office for National Statistics, 2000).

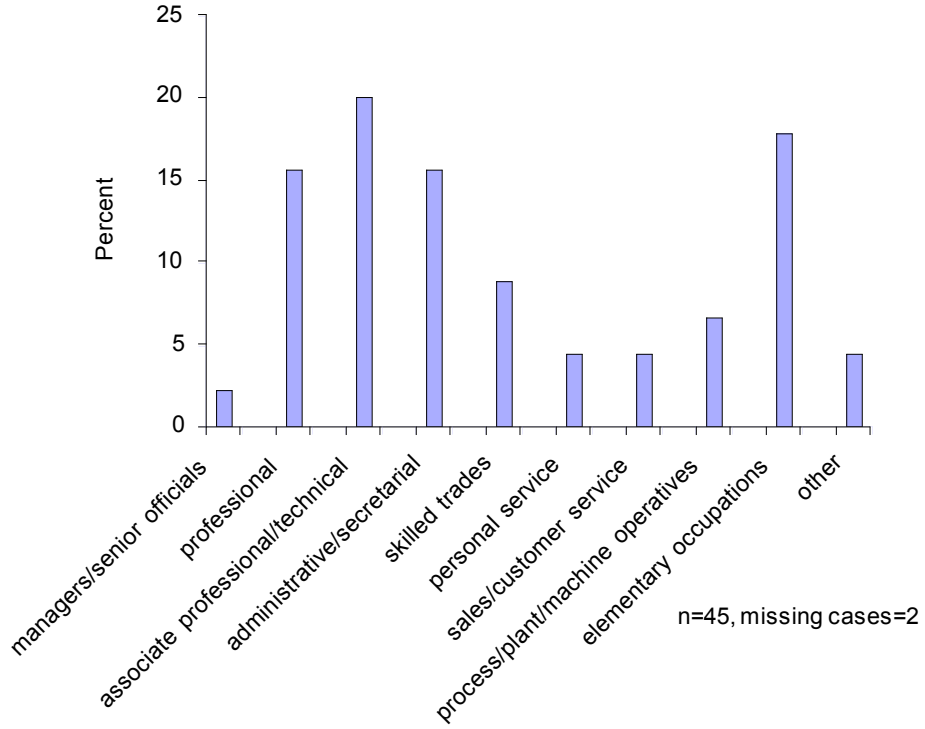


Figure 7. Job classification of survey respondents in work

As we can see from Figure 8, overall the sample had reached a high level of education, 58% having achieved A level/equivalent, or higher.

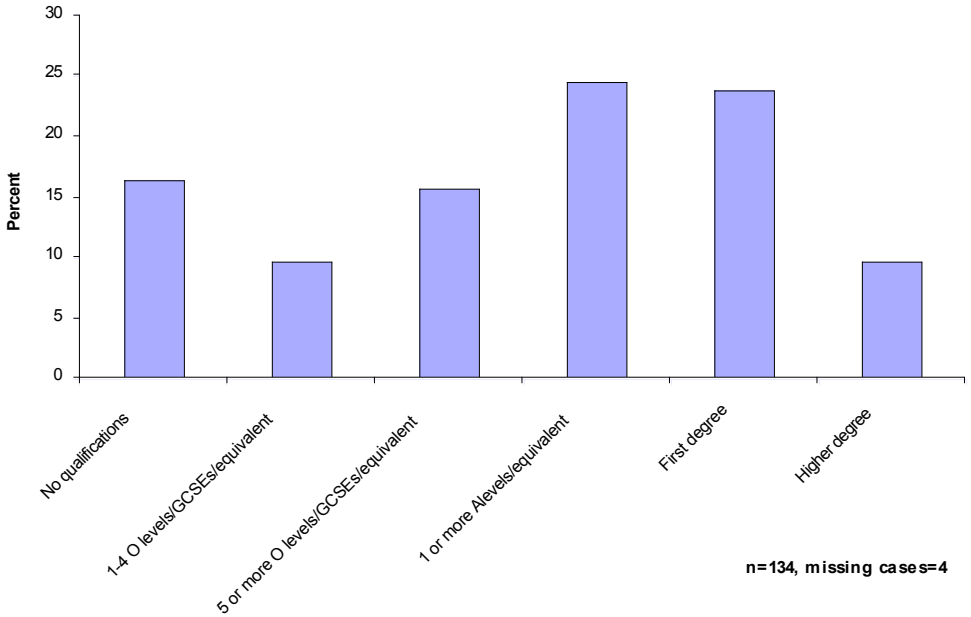


Figure 8. Level of education reached by survey respondents

In terms of marital status, most (77%) respondents were single and had never been married (see Figure 9).

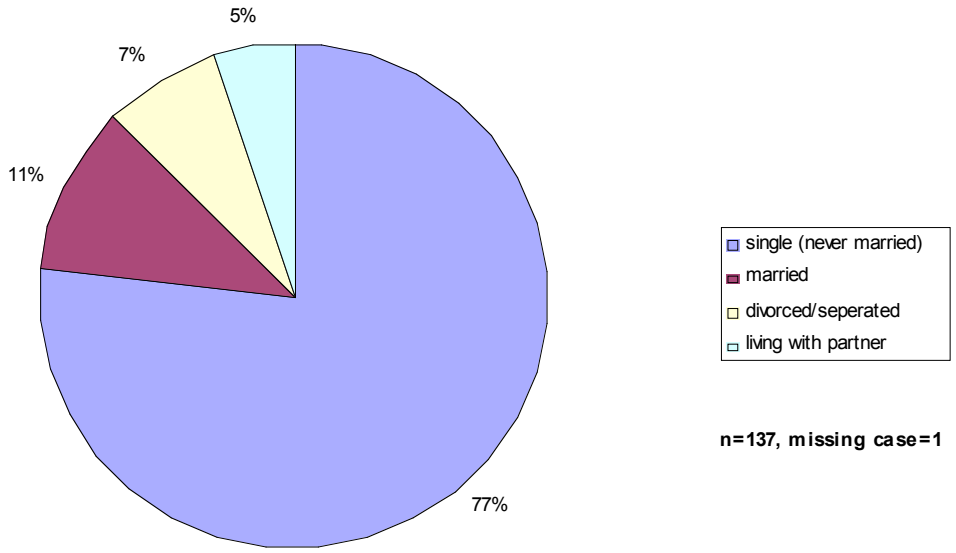


Figure 9. Marital status of survey respondents

Over half (56%) of the sample were living with family, whilst a quarter lived alone. 10% were in a supported residential situation. The rest either lived in university accommodation, group homes or shared with friends (see Table 3).

Type of residential situation	Frequency	Valid percent
living with family	75	56
living alone	34	25
sharing with friends	6	4
living in supported accommodation	13	10
living in group home	2	1
University accommodation	4	3
Other	1	1
Total	**133**	**100**

Table 3. Residential status of survey respondents

With respect to social contact (offline), 67% of the sample respondents were members of a club or group, whilst 60% spent time with friends at least once every two weeks (see Figure 10).

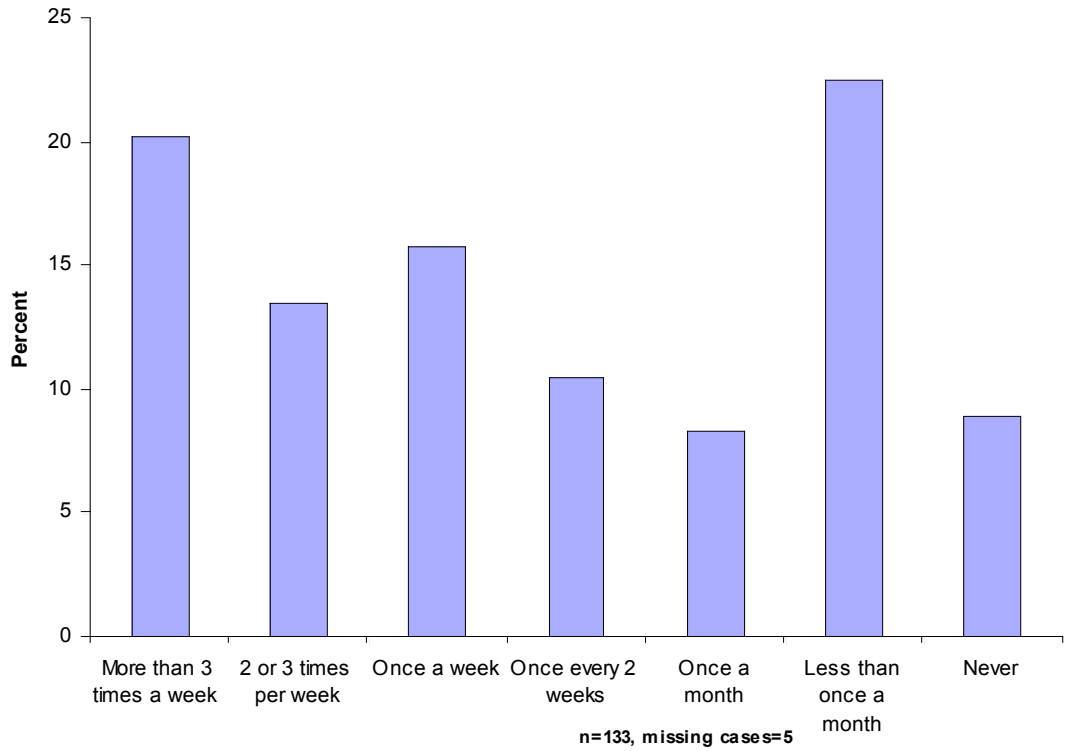


Figure 10. Frequency of contact with friends (offline) of survey respondents

Use of computers and the Internet

Analysis indicated a high level of computer and Internet use in this sample. The rates of various computer and Internet-related activities within the whole sample (n=138) are given below and should not be interpreted as a reflection of the target population as a whole.

- 95% of respondents are computer users
- 91% are Internet users (missing cases=2)
- 83% use the Internet to communicate with other people (missing cases=2)
- 83% use email (65% frequently, 18% rarely, missing cases=2)
- 61% participate in some kind of online forums, e.g. chat rooms, online discussions, newsgroups, bulletin boards (36% frequently, 25% rarely, missing cases=3)

- 53% participate in asynchronous online groups, e.g. newsgroups, bulletin boards (30% frequently, 23% rarely, missing cases=7)
- 49% participate in synchronous online forums, e.g. chat rooms, online discussions (29% frequently, 20% rarely, missing cases=5)

The proportions of non-computer/Internet/Internet-based communication users were low. Below is a summary of reasons for non-use.

Reasons for not using computers (7 people were non-computer users):

- Not been taught how to use computers (1 person)
- Do not like computers (2)
- No reason to use computers (3)
- Medical/physical reasons (2)
- No computer at home (1)
- Confusing information (1)
- Home access limited by other householder's needs (1)
- Do not want to use computers (1)

Reasons for not using the Internet (5 people were computer users but not Internet users):

- Not been taught how to use the Internet (2 people)
- Do not like the Internet (1)
- No reason to use the Internet (1)
- Do not want to use the Internet (2)
- No Internet access at home (2)
- Not easy to get to places to use the Internet (3)

Reasons for not using Internet-based communication (10 people were Internet users but did not use it for communication):

- Not been taught how to use the Internet to communicate with other people (3 people)
- Do not like using the Internet to communicate with other people (2)
- No reason to use the Internet to communicate with other people (2)
- Do not want to use the Internet to communicate with other people(2)
- Lack of email access (1)
- "Social isolation," respondent had no-one they could contact (1)

Places of access

As seen in Table 4 the main place of use of the Internet for this sample was in the home (75%), with some fairly large proportions using the Internet in more public venues, for example schools, universities and public libraries. The proportions of HFA/AS people accessing computers at the various locations were very similar to the figures obtained for Internet access.

Location	% who access Internet here (n=125)
Home	75
School/university	43
Public library	34
Work	26
Another person's home	24
Internet café	18
Club/community venue	4
Mobile use	2
Day centre	2

Table 4. Place of access of survey respondents

How much time is being spent using computers, the Internet and Internet-based communication by those who use it?

Figure 11 shows the distribution of time spent using computers for work/study purposes. 57% of respondents spend 2 hours or more per week using computers for such reasons.

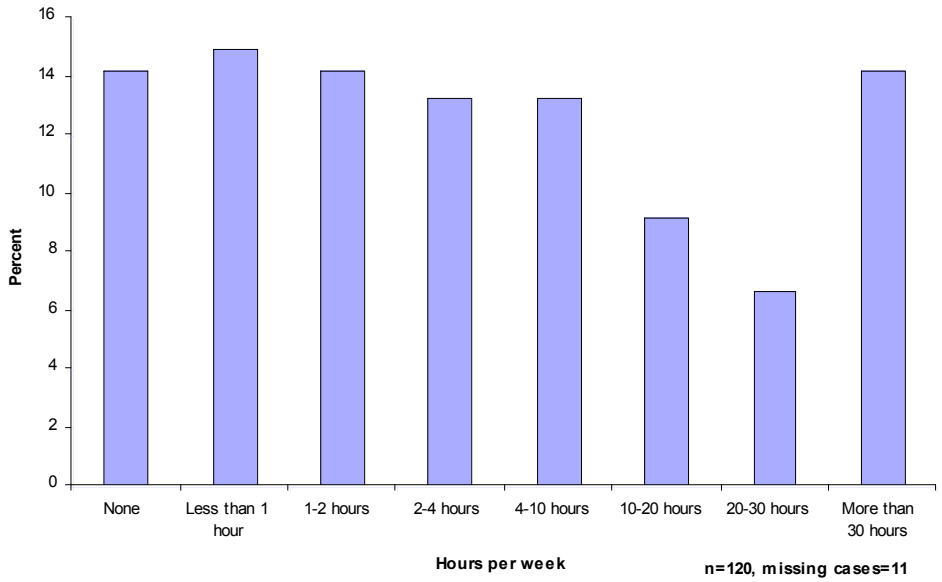


Figure 11. Work/study time spent on computers by users

More time seems to be spent using computers for leisure purposes, with 63% of respondents spending 4 or more hours per week of their time in this way (see Figure 12).

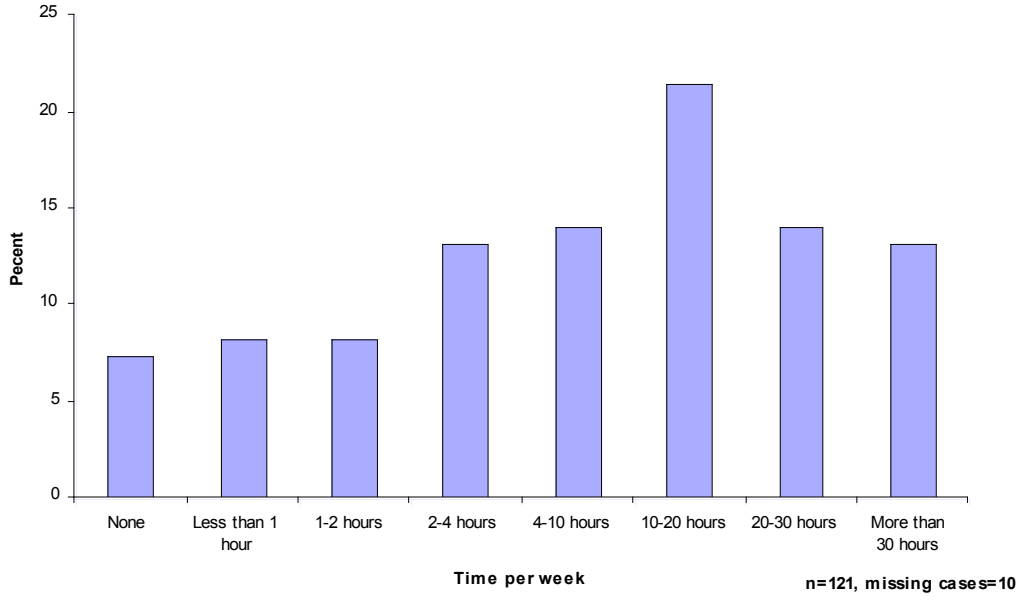


Figure 12. Leisure time spent on computers by users

Figure 13 shows the distribution of time spent using the Internet by respondents. 70% of Internet users were spending 4 or more hours per week online. Of those people who used the Internet for communication, 60% were engaged in this activity for 2 or more hours per week (see Figure 14).

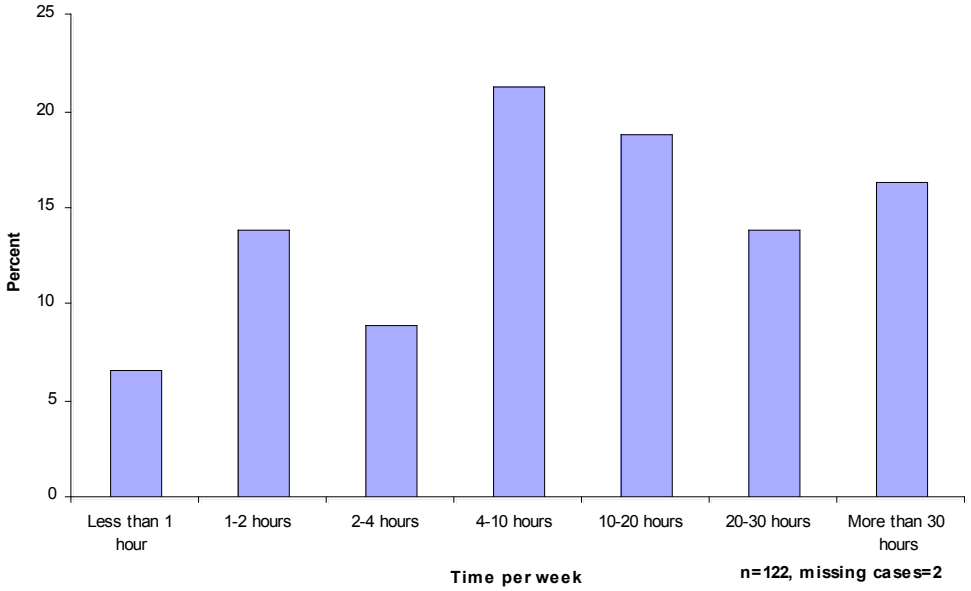


Figure 13. Time spent on the Internet by users

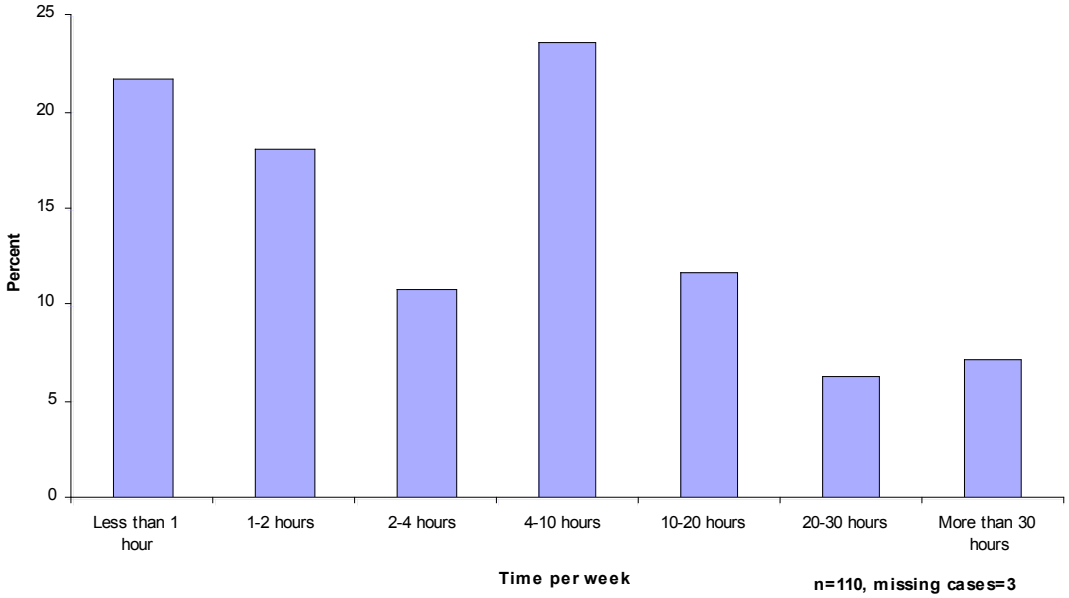


Figure 14. Time spent on Internet-based communication by users

What are people using computers for?

As can be seen from Table 5, computers were used most frequently to access the Internet (88%), sending email (69%) and creating documents (63%).

Activity	% computer users who frequently engage
Access Internet (missing cases=2)	88 (n=129)
Send email (missing cases=2)	69 (n=129)
Creating documents (missing cases=2)	63 (n=129)
Information storage (missing cases=2)	48 (n=129)
Play games (missing cases=2)	40 (n=129)
Digital photograph storage (missing cases=3)	27 (n=128)
Financial records (missing cases=3)	21 (n=128)
Watch DVDs (missing cases=2)	18 (n=129)
Education training courses (missing cases=4)	16 (n=127)
Artistic/media production (missing cases=3)	14 (n=128)
Software development (missing cases=2)	11 (n=129)

Table 5. Uses of computers

What are people using the Internet for?

People were using the Internet most often to send email (77%), look for information about hobbies or interests (71%) and "surfing" (57%) (see Table 6).

Activity	% users who frequently engage
Email (missing cases=2)	77 (n=122)
Looking for information re hobby/interest (missing cases=2)	71 (n=122)
Surfing (missing cases=2)	57 (n=122)
Obtaining news reports (missing cases=2)	53 (n=122)
Research for work/study (missing cases=2)	52 (n=122)
Obtaining health/medical information (missing cases=3)	37 (n=121)
Shopping (missing cases=3)	31 (n=121)
Take part in chat rooms/online discussions (missing cases=3)	32 (n=121)
Obtaining travel information (missing cases=2)	28 (n=122)
Check weather reports (missing cases=3)	27 (n=121)
Banking (missing cases=3)	26 (n=121)
Listen/download music (missing cases=3)	24 (n=121)
Access video/audio clips (missing cases=1)	24 (n=123)
Check sports scores/reports (missing cases=2)	20 (n=122)
Play games (missing cases=3)	22 (n=121)
Web page production (missing cases=3)	18 (n=121)
Looking for jobs (missing cases=2%)	16 (n=122)
Obtaining holiday information (missing cases=2)	13 (n=122)
Booking travel or holiday services (missing cases=2)	12 (n=122)
Education/training courses (missing cases=2)	9 (n=122)

Table 6. Uses of the Internet

How is the Internet being used for communication?

The most frequently occurring type of Internet-based communication was the exchange of emails with family/friends. Table 7 shows the level of use of all types of Internet-based communication.

Activity	% users who frequently engage
Exchange email with family/friends (missing cases=2)	72 (n=111)
Exchange email with other people for work/study purposes (missing cases=4)	49 (n=109)
Exchange emails with online groups (missing cases=4)	36 (n=109)
Exchange email with people who are not family/friends for non-work purposes (missing cases=2)	30 (n=111)
Take part in chat rooms or online discussions (missing cases=3)	28 (n=110)
Take part in MUDs/MOOs (missing cases=5)	5 (n=108)

Table 7. Types of Internet-based communication

How does Internet-based communication fit into the context of other types of communication?

Respondents were asked to indicate how much they did/did not like various forms of communication a) when interacting with friends, b) when interacting with people who were not friends. Tables 8 and 9 show the responses of those people who had ever used the Internet for communication (n=117).

When communicating with friends (see Table 8), email was the option which received the most responses of "like it a lot" (63%), face-to-face contact also being popular (54% liked it a lot). Live online chat seemed a lot less popular, only 34% liked it a lot and 38% did not like it. Telephone contact with friends was the least preferred mode of communicating with friends.

Form of communication	Like it a lot %	Like it a little %	Don't like it %
Email (n=112, missing cases=5)	63	32	5
Face-to-face (n=115, missing cases=2)	54	39	7
Text messaging (n=102, missing cases=7)	37	29	34
Postal (n=111, missing cases=5)	34	36	30
Live online chat (n=98, missing cases=9)	34	28	38
Telephone (n=113, missing cases=4)	28	43	29

Table 8. Preferences for communicating with friends (HFA/AS survey)

For this sample face-to-face communication was a lot less popular way of communicating with non-friends (see Table 9) in comparison to communicating with friends; only 14% liked it a lot and 42% did not like it (compared with figures of 54% and 7% when communicating with friends). Again email was the most preferred way of communicating in this type of interaction.

Form of communication	Like it a lot %	Like it a little %	Don't like it %
Email (n=112, missing cases=3)	47	40	13
Postal (n=111, missing cases=6)	26	53	21
Face-to-face (n=111, missing cases=5)	14	44	42
Text messaging (n=98, missing cases=11)	13	26	61
Live online chat (n=99, missing cases=8)	11	28	61
Telephone (n=111, missing cases=6)	9	42	49

Table 9. Communication preferences with non-friends (HFA/AS survey)

66% of people who use the Internet for communication said they would miss Internet-based communication with other people a lot if it were no longer available (n=105, missing cases=8).

Why are people motivated to take part in online forums?

In order to begin exploring participants' motivations for participation in online forums, a series of statements were given with a 4 point Likert scale of responses (strongly agree, agree, disagree, strongly disagree). Table 10 summarises their reactions to these statements:

Take part in online forums…	**% strongly agree**	**% strongly agree OR agree**
to contact people with similar hobby/interest	47	89
because enjoy this way of communicating	32	82
to find out information	31	78
to make contact with other people who have ASD	25	56
to feel part of a community	25	64
to get advice	22	68
to meet new people*	10	64

Table 10. Motivations for taking part in online groups
(n=72, missing cases=12 except *n=70, missing cases=14)

From this the strongest motivations for online group participation seem to relate to:

- Contact with others who have a similar hobby or interest
- Enjoyment of this form of communication
- Search for information

It does not seem that contact with others who have an ASD, or to meet new people, were particularly high motivations for these people to participate in online groups.

Who are the users of computers, the Internet, Internet-based communication and online groups?

In this sample a larger proportion of women used the Internet for communication: 92% compared to 79% of men. Statistically, however, this did not quite reach significance ($p<0.07$). However women were significantly more likely to participate in online groups (email or live chat): 77% compared to 57% of men ($\chi^2=4.678$, d.f.=1, n=132, phi=0.188, p <0 .031).

As shown in Table 11, people who had a job were significantly more likely than those neither in work nor fulltime education, to use computers, the Internet, and Internet-based communication as well as participate in online groups:

Activity	% of employed people who engage	% people neither in work nor fulltime education who engage	Fisher's Exact Test
Use computers	100 (n=46)	86 (n=51)	p<0.01
Use Internet	100 (n=45)	78 (n=50)	p<0.001
Use Internet-based communication	91 (n=45)	72 (n=50)	p<0.02
Participate in online groups	78 (n=45)	51 (n=49)	p<0.01

Table 11. Associations between employment status and use of computers, Internet, Internet -based communication and online forums

Compared to respondents neither in full time education nor work, students were also significantly more likely to use computers and the Internet, although they were no more likely to use the Internet for communication or take part in online groups (Table 12).

Activity	% of people in fulltime education who engage	% people neither in work nor fulltime education who engage	Fisher's Exact Test
Use computers	100 (n=41)	86 (n=51)	p<0.02
Use Internet	98 (n=41)	78 (n=50)	p<0.01
Use Internet-based communication	88 (n=41)	72 (n=50)	p<0.08
Participate in online groups	59 (n=39)	51 (n=49)	p<0.5

Table 12. Associations between educational status and use of computers, Internet, and Internet-based communication and online forums

How does computer/Internet/Internet-based communication use and online group participation relate to social involvement?

People with lower levels of offline contact with friends are significantly more likely to be involved in online groups. 56% of people who spent time with friends once a week or more were involved in online groups of some kind whereas of those who had such contact once a fortnight or less, 74% were online group participants (χ^2 =4.695, d.f.=1, n=128, phi=0.192, p<0.03). Relationships were not found between how often people spent time with friends and their status as a computer/Internet/Internet-based communication user.

There was a negative relationship between reported level of offline contact with friends and time spent on the Internet. People with a higher level of reported offline contact with friends (spending time with them once a week or more) were significantly (χ^2=6.868, d.f.=1, n=123, phi=0.236, p<0.009) more likely to report a lower level of Internet use (less than ten hours per week). Such relationships were not evident however between level of offline contact with friends and time spent on computers or time spent communicating via the Internet.

There was a small difference between people with low and high levels of offline contact with friends in terms of how often they exchanged emails with groups.

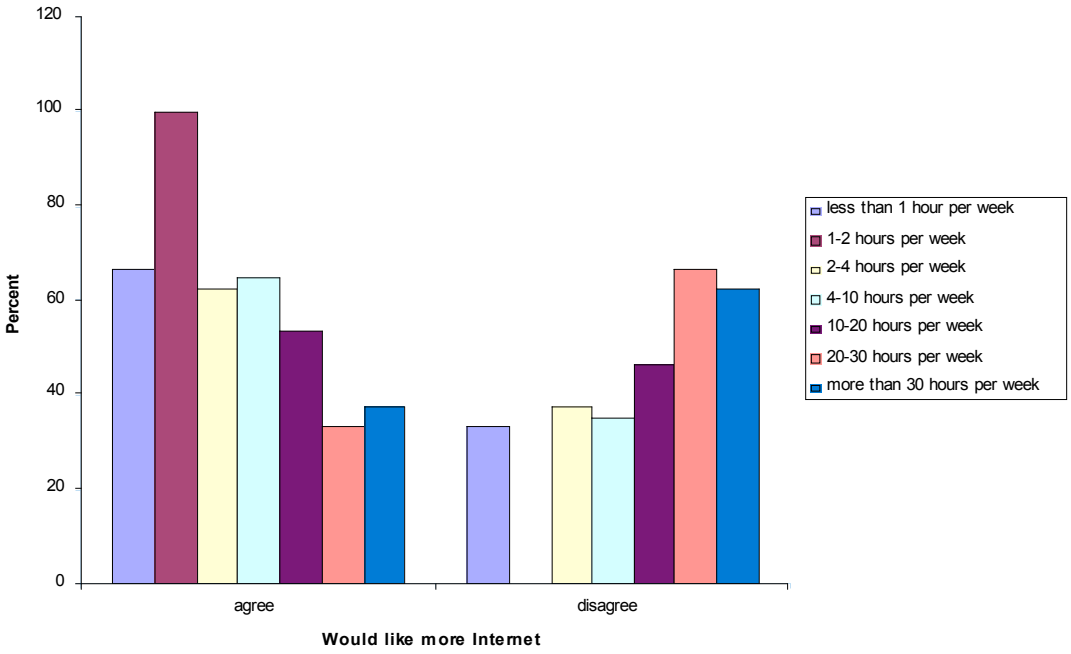
This is a negative relationship as shown in Table 13. People who spent time with friends more often were significantly ($\chi^2=11.36$, d.f.=2, n=106, $p<0.003$) less likely to frequently exchange email with online groups.

How often exchange email with online groups	How often spend time with friends	
	Once a week	Once every 2 weeks or less
Frequently	29.4%	43.6%
Rarely	19.6%	36.4%
Never	51.0%	20.0%
TOTAL	100%	100%

Table 13. Frequency of offline contact with friends by frequency of email exchange with online groups

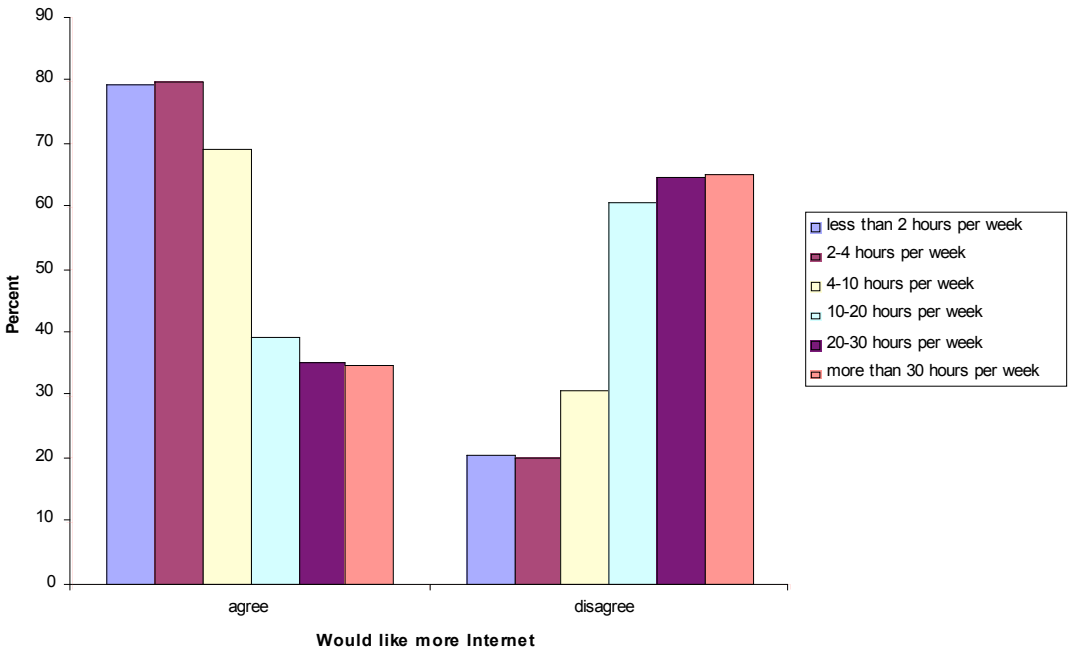
What are the possible factors influencing people's satisfaction with their level of computer/Internet use?

There was a significant negative relationship between a desire for more computer or Internet use and the amounts of time a respondent was spending on computers (for leisure purposes), Internet or communication via the Internet. Figures 15-17 illustrate the relationship between desire for more Internet use and the time spent on computers, the Internet and Internet-based communication, and show a similar profile to the figures obtained when a desire for more computer use was analysed with respect to the various time variables.



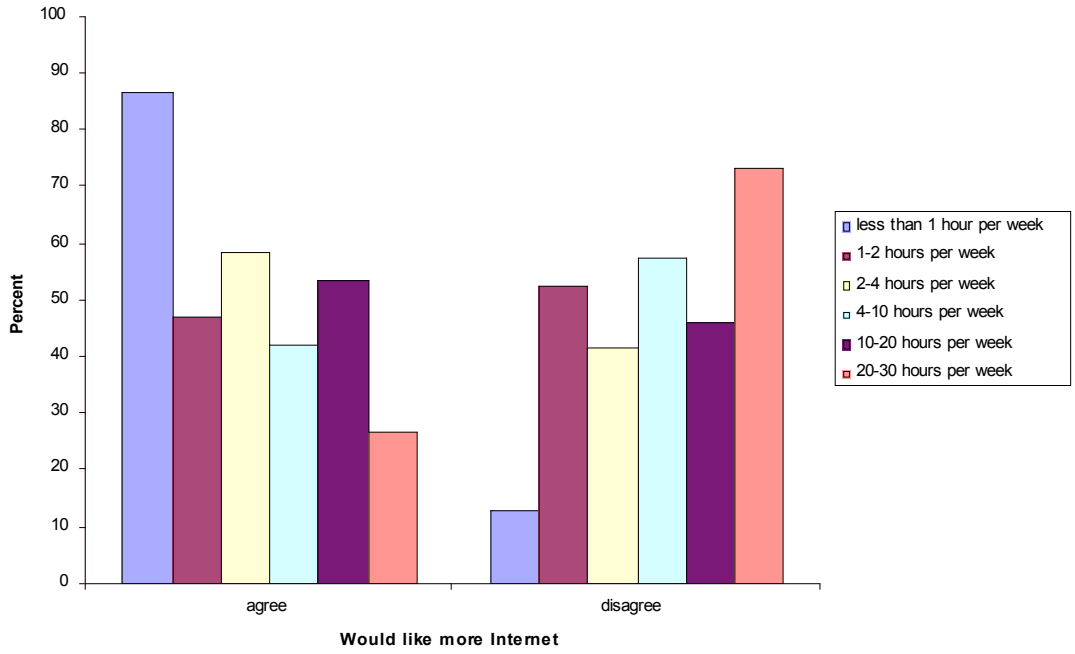
χ^2= 13.988, d.f.=6, n=114, p<0.03

Figure 15. Leisure time spent on computer and desire for more Internet



χ^2=18.590, d.f.=5, n=120, p<0.002

Figure 16. Time spent on the Internet and desire for more Internet



χ^2=16.408, d.f.=5, n=108, p<0.006

Figure 17. Time spent communicating on the Internet and desire for more Internet

It seems that the place of access to computers is a relevant factor. 77% of people who do not use computers at home would like to be able to use the Internet more, compared to 50% of those who do use computers at home (χ^2=5.987, d.f.=1, n=120, phi=0.223, p<0 .01). A similar association was evident when considering the desire to use computers more (χ^2=5.745, d.f.=1, n=122, phi=0.217, p< 0.02).

The public library is the other place of computer access which seems to be associated with a desire for more computer or Internet use. 77% of those who use computers at a library would like more Internet access, whereas the figure for those who did not access computers at a library was 46% (χ^2=10.421, d.f.=1, n=120, phi=0.295, p<0.001). Again a similar pattern was evident for the desire for more computer access and use of computers at a library (χ^2=5.579, d.f.=1, n=122, phi=0.214, p<0.02).

How do communication preferences relate to personal characteristics?

Analyses of the whole sample showed associations between some personal characteristics and predilection for types of communication.

When considering contact with friends:

- Telephone was significantly less appealing as a mode of communication for women as compared to men (χ^2=12.776, d.f.=2, n=132, p<0.002). 47% of women did not like it as opposed to 20% of men.

Regarding contact with people who were not friends:

- Younger people had a significantly higher preference for live online chat (χ^2=6.581, d.f.=2, n=110, p<0.04) and text messaging (χ^2=7.089, d.f.=2, n=109, p<0.03). 17% of 16-29 year olds liked live online chat a lot compared to 4% of 30-49 year olds and 0% of over 50s. 21% of 16-29 year olds liked text messaging a lot compared to 3% of 30-49 year olds and 8% of over 50s.
- People who were older were more likely to like postal contact a lot (χ^2=6.673, d.f.=2, n=132, p<0.04). 40% of over 50s said they liked it a lot compared to 36% of 30-49 year olds and 17% of 16-29 year olds.

How do communication preferences relate to level of social contact?

People with higher levels of offline contact with friends were significantly more likely to say they liked the following types of communication a lot:

Type of communication	Type of contact	Fisher's Exact Test	n
Text messaging	Friends	p<0.02	112
Face-to-face	Friends	p<0.0004	130

The following types of communication were more likely to appeal to people who had lower levels of offline contact with friends:

Type of communication	Type of contact	Fisher's Exact Test	n
Email	Friends	p<0.01	109
Postal	Non-friends	p<0.01	125

How do communication preferences and behaviours relate to each other?

Associations between communication preferences

The data were analysed to see if people who enjoyed one type of communication were more or less likely to also enjoy others. Positive associations were apparent between communication preferences as shown below:

Type of communication	Type of communication	Fisher's Exact Test	n
Postal contact with friends	Email contact with friends	$p<0.0003$	110
Postal contact with non-friends	Email contact with non-friends	$p<0.001$	110
Text contact with non-friends	Live online chat with non-friends	$p<0.004$	96

Although there was no significant association between a liking for email and for live online chat, there was a significant positive association between how often people exchanged emails with online groups and how often they took part in chat rooms (Fisher's: $p<0.001$, $n=108$).

Associations between online group participation and communication preferences

People who were members of online groups were more likely to prefer certain types of communication:

Type of communication	Type of contact	Fisher's Exact Test	n
Live online chat	Friends	$p<0.01$	97
Email	Non-friends	$p<0.05$	110

Members of online groups were less likely to prefer the following types of communication:

Type of communication	Type of contact	Fisher's Exact Test	n
Telephone	Friends	p<0.001	127
Face-to-face	Non-friends	p<0.002	124
Telephone	Non friends	p<0.02	124

Associations between value attributed to Internet-based communication and frequency of such behaviours

There was a significant positive association between the degree to which people would miss Internet-based communication and how often they exchanged email with an online group and also the frequency of participation in chat rooms. There was also a tendency that people who frequently emailed family or friends would miss Internet-based communication a lot, but the association did not reach significance:

Type of Internet-based communication	Fisher's Exact Test	n
Exchange email with family or friends	p<0.06	102
Exchange email with online group	p<0.02	100
Participate in chat room	p<0.04	101

There were no such associations between how much people would miss Internet-based communication and how often they participated in MUDs or MOOs, exchanged emails for work, or exchanged emails with people who were not friends/family for non work/study purposes.

How do reasons for being involved in online groups relate to other personal factors?

Respondents were asked to indicate their strength of agreement or disagreement with a series of statements pertaining to their reason for online group participation:

1. I take part in online groups or chat rooms because it enables me to make contact with people who have similar hobbies or interests to mine
2. I take part in online groups or chat rooms because I enjoy this way of communicating with other people
3. I take part in online groups or chat rooms because I can make contact with other people who have an autistic spectrum disorder
4. I take part in online groups or chat rooms so I can find out information
5. I take part in online groups or chat rooms as a way of getting advice about a problem
6. **I take part in online groups or chat rooms to meet new people**
7. I take part in online groups or chat rooms because it makes me feel part of a community

People who agreed with statement 6 were significantly more likely to be younger ($\chi^2=24.974$, d.f.=2, n=70, $p<0.000004$) or have a high level of contact with friends offline ($\chi^2=6.486$, d.f.=1, n=70, $p<0.01$).

How does level of contact with friends relate to other personal characteristics?

There was a moderate negative relationship between a respondent's age and how often he/she spent time with friends (Spearman's rho=0.436, n=131, $p<0.001$).

People who were in fulltime education tend to spend time with friends more often than those who are not. 78% of those in fulltime education saw friends at least once a week or more compared to 39% of those who were not in fulltime education. The association was a moderate one ($\chi^2=15.366$, d.f.=1, n=130, phi=0.344, $p<0.0001$). It should be noted that there was a strong positive association between age group and whether a respondent was in fulltime education ($\chi^2=34.839$, d.f.=2, n=134, $p<0.00000003$).

Summary

This was a large data set in terms of the range of variables which were obtained from the 138 respondents who took part in the survey. This chapter has presented a descriptive overview of the characteristics of the sample in terms of demographic and personal characteristics, as well as trends which emerged as significant in terms of use of computers, the Internet and Internet-based communication. The key findings as they pertain to the objectives underlying the survey are summarised below:

To find out how access to the Internet is obtained by people with AS or HFA

- The main place where the Internet was accessed was at home but there was also a fairly high level of access in public places such as libraries, schools and colleges.

To find out the amount of time being spent online by people with AS or HFA and the level of satisfaction with this quantity

- Internet users were typically spending between 4 and 10 hours per week online and between 2 and 4 hours per week using the Internet for communication.
- People who accessed the Internet at home were significantly more likely to be satisfied with their level of computer and Internet use than people without home access.

To place CMC use in the context of other forms of Internet use, computer use, social contact and communication

- The most popular use of computers was Internet access, and the most popular Internet activity was the use of email.
- Email was the most popular way of communicating with other people and telephone was the least popular.
- People with lower levels of offline social contact were more likely to take part in online groups.
- There was an inverse relationship between the level of offline contact with friends and the time spent on the Internet.

To explore the reasons why people with AS or HFA use the Internet for communication

- The two most popular reasons for taking part in online groups were contact with others with or shared hobby or interest, and enjoyment of this type of communication.
- Younger people and those with a higher level of social contact were more likely to agree that they took part in online groups to meet new people.
- The degree to which people would miss Internet-based communication was associated with how often they exchanged email with online groups and also with how often they took part in chat rooms.

CHAPTER 6: SURVEY DISCUSSION

In this chapter I shall discuss the survey findings in relation to the methods by which they were obtained and also current research and knowledge. The extent to which they meet the objectives originally set will also be examined as well as their implications for the interview phase of the study.

Characteristics of the sample

As discussed previously, the people who took part in the survey comprised a non-probability sample and so claims of representativeness cannot be made. However, given the exploratory nature of the study, attempts were made to obtain responses from as wide a range of people as possible, and it is appropriate to examine the characteristics of this group when contextualising the main survey findings.

60% of respondents completed an AQ. The mean score for this group was 35.3 (s.d.=9.2). This is comparable to previously published findings of scores for people with HFA/AS (Baron-Cohen et al., 2003; Baron-Cohen et al., 2005; Baron-Cohen et al., 2001; Ring et al., 2008; Wheelwright et al., 2006; Woodbury-Smith et al., 2005) suggesting that the subgroup who completed the AQ had autistic traits at a clinically significant level in comparison to the general population. Although we were unable to verify clinical diagnoses, a large majority (90%) were able to give a response to the question which asked about age at diagnosis. Another parallel with other studies which is also worthy of mention is that a cut-off score of 26 would have excluded 19% of this sample as not having a clinically significant level of autistic traits, whilst Woodbury-Smith et al (2005), who suggested that particular score, found that it failed to identify 17% of their sample.

It was disappointing that not all the sample completed the AQ, which was requested as an option after the Internet questionnaire had been completed. With hindsight perhaps both questionnaires should have been presented together. However this may have been off putting to respondents due to the lengthy package it would have created, as well as the possible reluctance by some to complete a diagnostic assessment. One of the early respondents stated

that he felt affronted by the implication that his diagnosis was being questioned.

In terms of age, as anticipated the sample obtained was skewed toward a younger age group (typically 20-29 years old). Prior to 1981, the year in which Lorna Wing published her descriptions of the disorder (Wing, 1981), few clinicians were aware of Asperger Syndrome, and it only became an official diagnostic category in the early 1990s (American Psychiatric Association, 1994; World Health Organization, 1993). According to Gillberg (1998) the term "high-functioning autism" was first used in 1981 by DeMyer et al, and does not as yet convey a universally agreed definition. Thus those people diagnosed as having Asperger syndrome or high-functioning autism are more likely to have been children in the 1980s or later.

The relatively recent awareness of AS/HFA is also reflected within this sample by the tendency toward diagnosis in adulthood, typically between 21 and 30 years of age.

As would be expected the large majority of respondents were men (72%). Wolff (1995) reported that sex ratios of incidence for Asperger syndrome and related conditions vary from 2.3:1 to 10:1. A population study by Ehlers and Gillberg (1993) suggests a ratio of 4:1.

In terms of ethnicity the sample was largely white British, with no representation of people of Asian, African or Caribbean backgrounds. Whilst this is disappointing it is probably not surprising. A recent report from the NAS concluded that autistic people from black and minority ethnic groups, and their families, are neglected by services. Individuals from these groups may miss out on diagnostic, educational, or support services due to the lack of awareness of professionals, as well as provision which fails to accommodate cultural and linguistic variations (Corbett & Perepa, 2007). There was a relatively large proportion (10%) of people who identified themselves as belonging to ethnic groups not specified on the questionnaire, and this may reflect the overseas respondents who volunteered for the survey in response to web-based adverts (who comprised 11% of the sample).

It is difficult to comment on whether the sample seems representative in terms of employment, education status, residential or marital status. Reviewing research into the adult outcomes for more able autistic individuals, Howlin (2000) found that results were extremely variable. The proportion in work ranged from 5 to 55% (compared to a figure of 34% in this study), and the

proportion living independently from 16 to 50% (compared to 25% for this study). Other methodological issues which have limited research into this area are small sample sizes, heterogeneity of the subject population, differences in subject selection procedures (prospective versus retrospective studies; clinic versus whole population studies), and differences in support provision, associated with geographical or socioeconomic variations (Tsatsanis, 2003).

There was a high level of computer use in the sample, which is not surprising given the nature of the research topic and the availability of a web version of the questionnaire. There was a higher proportion of Internet users than was found in a general population survey (Dutton et al., 2005) which established that 63% of the population use computers, and 61% use the Internet, compared to rates of 95% and 91% respectively in the HFA/AS sample. It should also be noted that within the general population Internet use is positively associated with younger age and earlier life stage (Dutton & Helsper, 2007); therefore, as this was a young sample, a higher rate of Internet use may be predicted.

In this study, women were more likely to take part in online groups (email or live chat). This finding may have parallels with research by Hamburger and Ben-Artzi (2000) who found that in women introversion was positively associated with the use of Internet-based chat and discussion groups, and suggest that the Internet provides a safe environment in which to engage in such activities to tackle the loneliness associated with the sparser social networks of introverted individuals. They hypothesise that women may be more self-conscious and aware of their mental state, being more likely to seek help online for their loneliness. To support this proposition they cite other studies that show that in stressful situations women are more likely to seek help (Leana & Feldman, 1991) as well as the finding of Kraut et al (1998) that Internet use increases loneliness in men more than women.

Having examined the diversity of personal characteristics of the sample obtained, I shall now explore how the findings relate to the objectives of the survey.

Objective 1: To find out how access to the Internet is obtained by people with AS or HFA

The main place of use of the Internet was in the home, although this was less prevalent than was found in a general population survey of Internet use, the Oxford Internet Survey (Dutton et al., 2005) as shown in Figure 18. A

substantial amount of access by HFA/AS people also takes place at public libraries or places of education, more so than in the general population. Access at Internet cafes is also more evident than in the general population. It seems that for this sample people are making the effort to get to places to access the Internet.

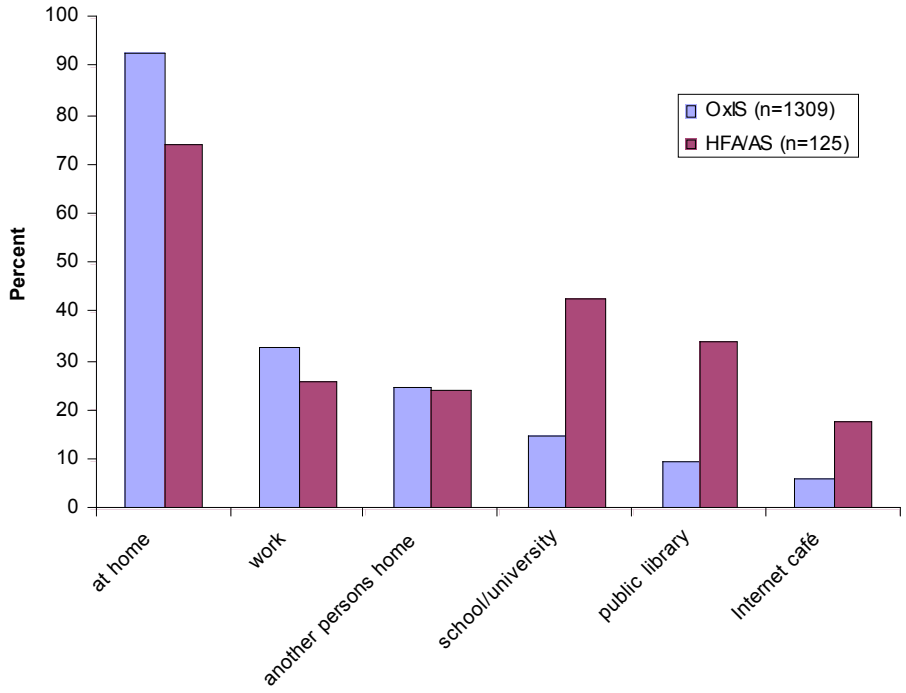


Figure 18. Places of Internet access used by survey respondents (HFA/AS) and Oxford Internet Institute Survey 2005 respondents (OxIS)

There is an implication that being in work or full time education has benefits in terms of providing access to computers and the Internet. People who had a job were more likely to use computers, the Internet, and Internet-based communication as well as take part in online groups. This may relate to issues of availability in the workplace and/or the financial benefit of being in work. Previous discussion of the digital divide indicated that low income was a major determinant of digital exclusion (see Chapter 3), compounded by lack of publicly available access to the Internet.

Respondents in fulltime education were also more likely to be users of computers or the Internet, again implying that access to the technology is more available to people in this situation. However fulltime students were no more likely to use the Internet for communication or to participate in online groups. This may relate to restrictions on time and access in places of education. It may also relate to the finding that being in fulltime education was positively

associated with level of offline contact with friends, such that there may be less motivation to use the Internet for social interaction and communication.

Objective 2: To find out the amount of time being spent online by people with AS or HFA and the level of satisfaction with this quantity

In terms of computer use, respondents were spending more time on computers for leisure than for work or study purposes, typically 4 to 10 hours per week compared to 2 to 4 hours per week. This may reflect the fact that 38% of the sample were neither in fulltime education nor had a job. Internet users were typically spending between 4 and 10 hours per week online and between 2 and 4 hours per week using the Internet for communication.

It seems that a low level of computer or Internet use is not typically through choice. There was an inverse relationship between a desire for more computer or Internet use and the amount of time spent on computers (for leisure purposes), Internet or Internet-based communication. There was also an implication that accessibility influenced satisfaction with amount of time online. People who access computers at home were more satisfied with their level of computer and Internet use than those who do not. Conversely, those who use computers at a public library were more likely to want more computer and Internet access than those who do not use library facilities.

Objective 3: To place CMC use in the context of other forms of computer use, Internet use, social contact and communication

The most popular use of computers was Internet access, and the most popular Internet activity was the use of email. Figure 19 shows a comparison between the findings of the Oxford Internet Institute Survey and this survey with regard to the proportions of Internet users who engage in the various types of Internet activities. It should be noted that the Oxford Internet Institute survey figures used in constructing this graph are based on all respondents who partake in a particular activity regardless of how often this occurs whereas the figures for the HFA/AS sample take into consideration only those who frequently engage. This may account for the slight differences in relative popularity between the two sets of figures. Also, due to some differences in categorisation of activities in the two surveys, there are some (looking for product information, looking up a fact and finding information on a hobby or interest) for which there is only

information displayed for one of the studies. The most striking differences between the two surveys are that the use of the Internet to obtain news reports, look for jobs and "chat" are more evident in the HFA/AS sample than the general population. However it must be acknowledged that the non-random sampling strategy in this study could well be the cause of bias particularly toward chat.

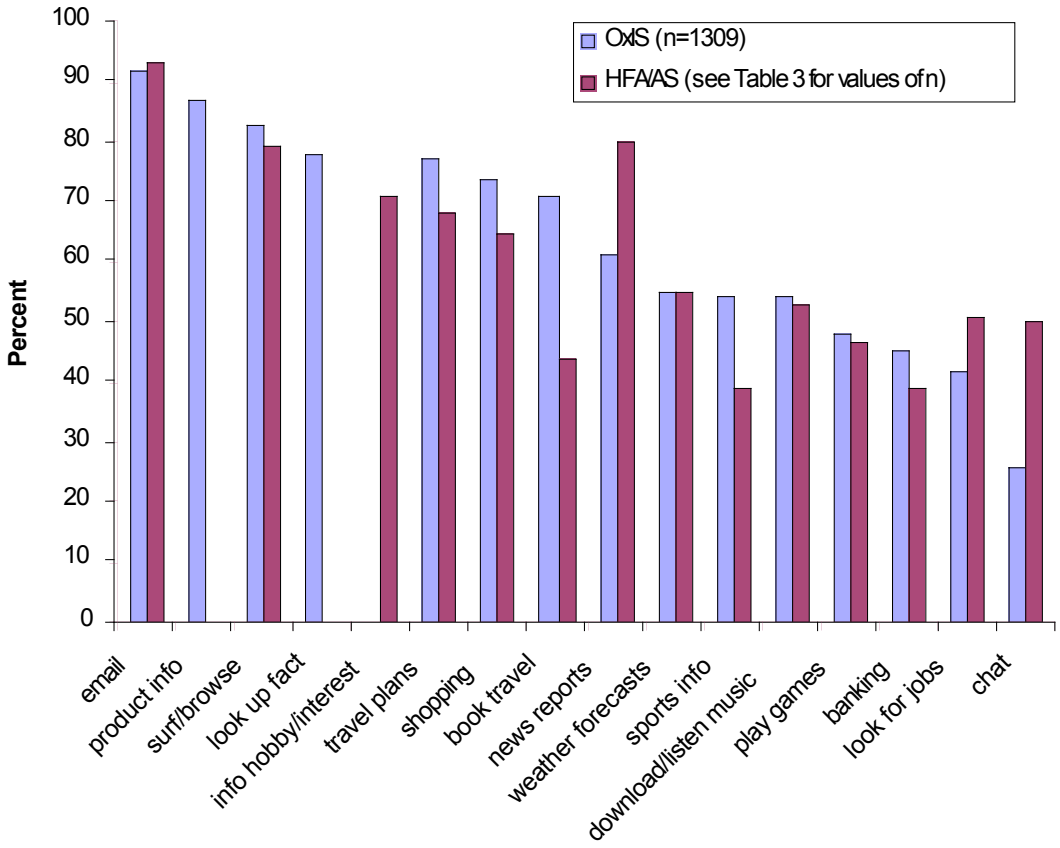


Figure 19. Internet functions used by survey respondents (HFA/AS) and the Oxford Internet Institute Survey 2005 respondents (OxIS)

Regarding other forms of social contact, people with lower levels of offline social contact were more likely to take part in online groups. This raises the issue of whether people whose levels of social contact are low are drawn to participate in online groups as a means of compensating for a lack of such contact, or whether online group involvement is something which is more appealing to people who do not like/engage regularly in face-to-face contact.

There are parallels with those studies which found positive associations between social use of the Internet and loneliness (Engelberg & Sjoberg, 2004; Morahan-Martin & Schumacher, 2003; Recchiuti, 2003), introversion (Hamburger & Ben-Artzi, 2000) or shyness (Recchiuti, 2003), as well as the

perceived benefits reported by such individuals when online (Roberts et al., 2001; Stritzke et al., 2004) as discussed in Chapter 3.

It is also worth speculating as to whether such online activity in some way increases participants' tendency to withdraw from real world contact, as early research into home Internet use by Kraut et al (1998) suggested. The current study found a negative relationship between the reported level of offline contact with friends and time spent on the Internet, as well as an inverse relationship between level of offline social contact and frequency of email exchange with online groups. However, Kraut et al's assertion was not substantiated by other studies, some of which even found a positive relationship between Internet use and offline social contact (Boase et al., 2006; Hampton & Wellman, 2002; Katz et al., 2001; 1998; Wellman et al., 2001). For lonely people or those who do not find offline interactions satisfying or comfortable, online interactions may offer an attractive alternative way of making social contact.

Within the study sample email was a very popular means of communication, when contacting friends as well as people who were not friends. As Figure 20 shows, it seems, perhaps, that asynchronous forms of communication, particularly those that are text-based, are preferable to synchronous forms of communication when interacting with strangers. There are elements of this trend when considering interaction with friends, the main exception being that face-to-face contact has a fairly high level of preference (see Figure 21).

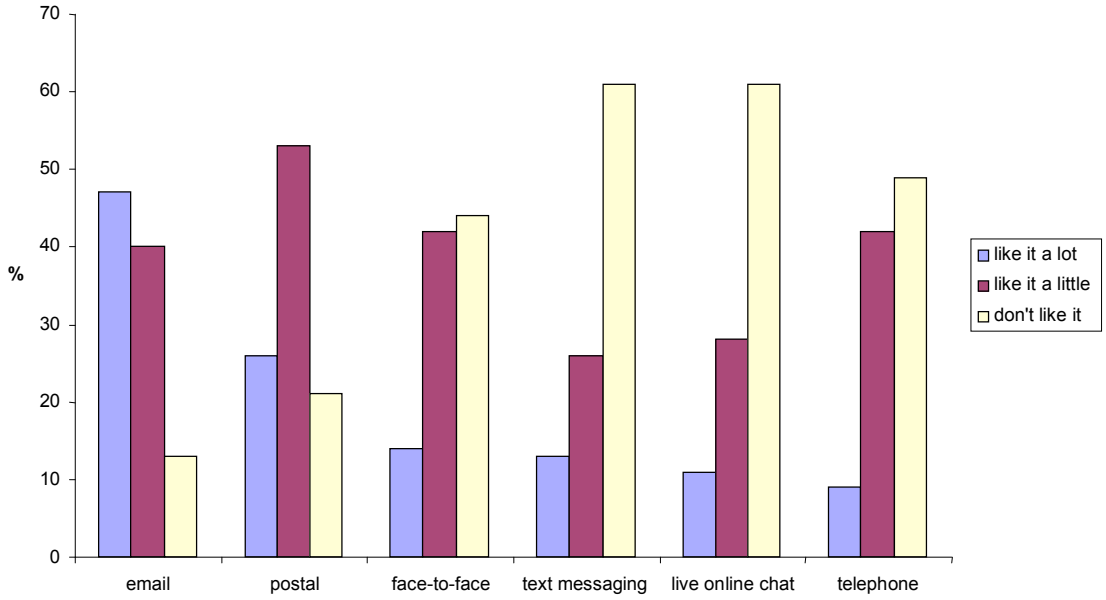


Figure 20. Preferences for communicating with non-friends

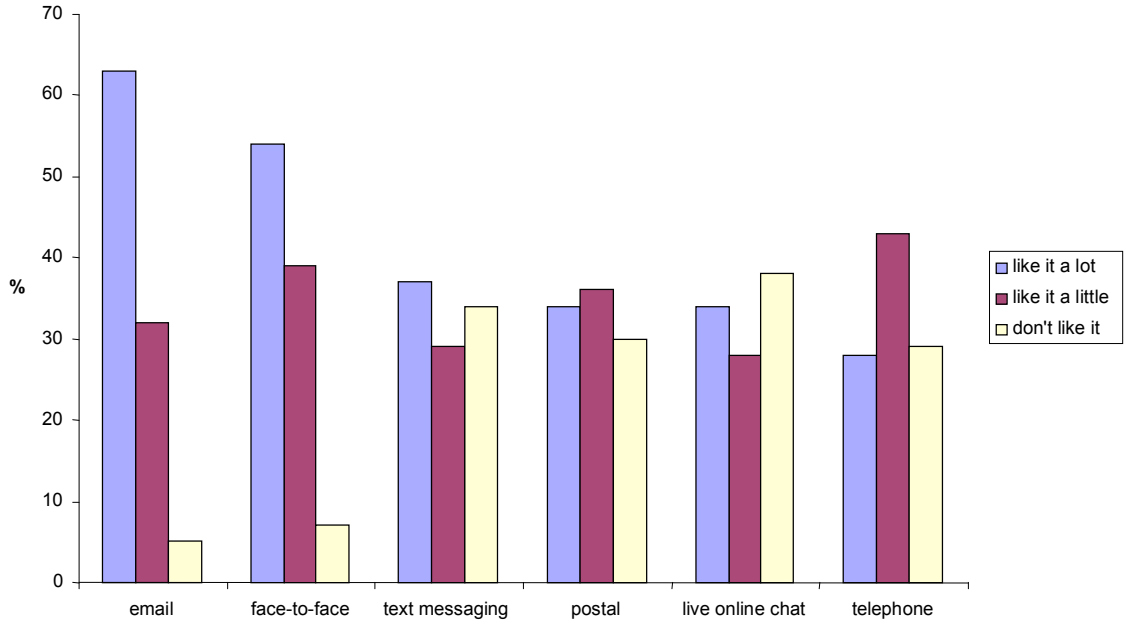


Figure 21. Preferences for communicating with friends

Although there are no directly comparable variables reported in the Oxford Internet Institute Survey, the relative popularity of different communication media in the general population might be inferred from the frequency of their use to contact friends a) close by and b) far away. As shown in Table 14, telephone communication seems to be a lot more popular in the general population, and email and written communication less so.

Type of communication	% who often use to contact friends close by	% who often use to contact friends far away
Phone	61	36
Visit	57	14
Email	12	14
Write	9	11

Table 14. Frequency of use of communication types with friends (Oxford Internet Institute Survey 2005)

The results of this study suggest that differences in the timing and pace of communication may be significant factors contributing to the appeal of online communication. As discussed in Chapter 3, online communication may afford people greater control over self-presentation, and the pace and content of communication, aspects which were particularly valued by people with

traumatic head injury affecting cognitive aspects of communication, interviewed by email in a study by Egan et al (2006).

When associations between respondents' preferences for various forms of communication were examined, there were further suggestions of possible parallels between less synchronous forms of communication (email and postal) and also between more immediate forms (text and online chat). Alternatively the association between liking of text messaging and live online chat could be a reflection of the communication preferences of younger members of the sample, which differed from those of older respondents.

Although there was no significant association between a liking for email and for live online chat, there was a significant positive association between how often people exchanged emails with online groups and how often they took part in chat rooms. Although these two forms of interaction differ in terms of synchronicity, their shared features are the potential to contact new groups of people, possibly with whom there is commonality, perhaps in a forum which has rules and is moderated, but which lacks the physical presence of the other participants and the necessity to deal with nonverbal communication. It is also possible to be more passive in one's interactions in such groups, and to be anonymous. As discussed in Chapter 3, current CMC theories and research imply that anonymity online may serve to create feelings of safety and reduce self-consciousness, with implications for self-expression, self-presentation and hyperpersonal (Walther, 1996) or intimate interactions, particularly for those who face difficulties with person-to-person communication and relationships (Amichai-Hamburger & Furnham, 2007; Joinson, 2004; McKenna et al., 2002; Morahan-Martin & Schumacher, 2003; Recchiuti, 2003; Roberts et al., 2001; Stritzke et al., 2004).

When considering the apparent lack of correlation between preference for email and synchronised online chat, it should be noted that data were collected at a time when instant messaging was a less common use of the Internet than it is today, and that it was a function which was predominantly used by young teenagers. Therefore people's responses may have been based on their experiences of group interactions in chat rooms, rather than the more one-to-one communication with people who were likely to be familiar acquaintances which is more typical of instant messaging. The data which were obtained in the subsequent interview stage of the project implied this was the case.

People who were members of online groups were less likely to prefer telephone contact with people (friends and non-friends) and also face-to-face contact with

non-friends. It could be hypothesised that comfort with these types of interaction, which involve synchronised speech can bring benefits in terms of "real life" friendships, making people less likely to feel a need for online group contact.

There were some interesting associations between people's preferences for certain types of communication and their level of social contact offline. People with higher levels of offline contact with friends were significantly more likely to enjoy face-to-face or text message contact with friends. It is possible that an inclination toward text or face-to-face contact may facilitate and maintain "real life" friendships.

People with lower levels of offline contact with friends were more likely to say that they liked email contact with friends or postal contact with non-friends. This could imply that email and postal contact are used to compensate for low levels of social contact. Alternatively it could be that a propensity for these types of communication modes (mediated, asynchronous, text-based) is associated with personal factors which hinder the formation of friendships in offline situations. As discussed in Chapter 3, there is a suggestion that certain personality types are more predisposed toward face-to-face communication than others; those who are more extrovert, those who are more spontaneous and reactive to incoming information (perceiving) and those who are more empathetic in their approach to situations (feeling) (Goby, 2006), or emotionally intelligent (Engelberg & Sjoberg, 2004). Similarly from a hyper-systemising perspective (Baron-Cohen, 2002a), autistic people are less suited to face-to-face communication, but have greater affinity for CMC as a result of their superior analytical skills.

Objective 4: To explore the reasons why people with AS or HFA do or do not use the Internet for communication

The discussion of findings for Objective 3 above has raised some possible reasons for respondents' use of Internet-based communication. Online communication may compensate for difficulties with spoken and/or face-to-face social interaction and the lack of offline social interaction which may result from such barriers. The different synchronicity of Internet-based communication, the use of text rather than speech, and the lack of nonverbal communication have been raised as possible factors which may make online interaction easier, perhaps more comfortable, for people with HFA/AS.

The questions focussing on people's reasons for taking part in online groups also give some indication of reasons for use of Internet-based communication. The two strongest motivations were contact with others who had a shared hobby or interest, and enjoyment of this type of communication. The latter reason does suggest that Internet-based communication offers a comfortable place in which to communicate for this group of autistic users. Although the sample as a whole did not see the potential to meet new people as a particularly strong motivation for online group participation, younger people and those with a higher level of offline social contact were more likely to acknowledge this as a reason. When considering these findings it should also be noted that age and level of offline contact with friends were negatively associated in this sample and it is not clear the degree of interplay between the two variables.

One can speculate as to whether there is a generational effect such that younger people are more engaged with Internet technology and its potential as a means of meeting other people, or perhaps that the drive to meet others is stronger in younger people. The 2007 Oxford Internet survey found that younger people, particularly students, were the most active users of the Internet for social communication purposes, as well as being more likely to use social networking sites, or make online friendships (Dutton & Helsper, 2007).

The positive association between level of offline contact with friends and agreement that one took part in online groups to meet new people, raises the question of cause and effect, that is whether taking part in online groups helps people to make new friends, or whether it is those who have more potential and success in developing friendships who are motivated to engage in online groups for this purpose. This may resonate with a social networks model of interpersonal communication, and research which indicated that the Internet supplements traditional social behaviour, as discussed in Chapter 3, or the assertion of Kraut et al (2002) that it is those whose existing social contact is good, who are more likely to benefit socially from the Internet.

Whilst the drive to meet new people online was not universal for the sample, other results imply that Internet-based communication has perhaps sociable appeal in terms of contacting other people. The degree to which people would miss Internet-based communication was associated with how often they exchanged email with online groups and also how often they took part in chat rooms. (There was also a tendency that people who frequently emailed family or friends would also miss it a lot, but the association did not quite reach

significance.) No such association was found however between how much people would miss Internet-based communication and how often they communicated for less sociable needs for example the exchange of emails for work/study purposes or with people who were not friends or family for non work/study purposes. There are possible parallels between these results and those of Papacharissi and Rubin (2000) who found that individuals whose online activities were primarily influenced by socially driven motives reported greater affinity for the Internet compared to those who were motivated by its informational utility.

Survey limitations

In the absence of effective centralised information on the target population to serve as a sampling frame, it was not possible to obtain a random sample of people with HFA or AS for the survey. Additionally due to the low prevalence of autism, associated with social and geographical isolation, as well as lower levels of awareness and service provision for those at the higher functioning end of the autistic spectrum, this was a population which was hard to locate, and therefore the target sample size proved to be unrealistic. In their review of strategies for researching hard-to-reach populations, Thompson and Phillips (2007, p1296) conclude: "To summarise the rather sparse literature on the topic, it is clear that the most productive approaches are those that use a judicious blend of strategies and techniques." In line with their research involving rare populations such as people with advanced Parkinson's disease, as well as that of Baker (2006) whose research involved parents and primary caregivers of children with autism, respondents were recruited from a number of different sources with the aim of obtaining a sample which could represent a range of views, needs and perspectives, as diverse as that occurring within the target population. The resulting non-probability sample appeared to be biased toward Internet users, which is probably not surprising given the research topic and the inclusion of a web version of the questionnaire. It should be noted also that the proportion of the general population who do not use the Internet is declining, and that Internet use is more prevalent in younger people, a group more represented within this survey sample, probably due to the relatively recent recognition of higher functioning autistic individuals, as already discussed. Therefore, although great effort was made to ensure data were obtained from non-users, there was limited potential to achieve this within a population which was hard to locate and which was likely to be skewed towards a younger age group.

Implications of the survey findings

This exploratory study has yielded a large amount of contextual data about the use of the Internet by a sample of people with HFA/AS. Due to difficulties accessing the target population, a non-probability sample was obtained for this study, which appears to be biased toward Internet users. It is therefore necessary to be cautious when interpreting the findings in terms of claims of generalisation. Although analysis of the data revealed associations between certain variables, this was a cross-sectional study, and causality cannot be inferred. However this is the first step into researching what was previously a largely unresearched topic, involving a difficult to access population. It has provided some descriptive information about the phenomenon as well as some speculative hypotheses and issues which require further investigation, in the first instance by means of the in depth interviews which constitute the second part of this project.

This study informed design of the second stage in terms of the media by which data were collected, that is by email or conventional post which were found to be the two most popular modes of communication for interaction with non-friends for the survey sample, from whom the interviewees would be selected. It also identified variables which should guide the choice of interview participants, variables which had emerged as significant, for example age, level of offline social contact, employment status, in order to obtain a diverse range of views.

In addition it also raised some interesting issues which guided the development of the interview guide:

- How does online interaction impact on life offline?
- Are online groups seen as a means of compensating for a lack of social contact?
- To what extent does Internet-based communication provide a more effective and comfortable means of expression for people with AS?
- What features of the Internet as a communication medium are appealing (for example the different pace of communication, the use of text instead of face-to-face or spoken communication)? Which are off putting?

The next chapter will present the findings of semi-structured interviews carried out with a smaller number of respondents to explore their experiences, motivations and perceptions of the Internet as a communication medium.

CHAPTER 7: INTERVIEW ANALYSIS

Introduction

Inevitably, due to the slow and variable pace of email facilitated interviewing, the second part of the study was conducted over a prolonged period of time. Email interviews involved between 22 and 82 postings back and forth, and took from 6 to 38 weeks to reach their conclusion. Interviews took place over a 14 month period, November 2005 – January 2007.

In this chapter I shall present the themes emergent from the data provided by people with HFA/AS when interviewed about their motivations, perceptions and experiences of the Internet as a communication medium. I shall begin by describing the personal and demographic background details of the interviewees, before presenting the themes and sub themes which resulted from analysis, including extracts from the interviews as illustrations of the interpretations made.

Characteristics of the sample

A total of 23 people were interviewed. 19 of these were users of the Internet and Internet-based communication and were interviewed by email. 3 people used the Internet but not for communication, whilst one did not use computers at all. This group of 4 was sent a series of open questions by post. Information from the survey was used to profile the sample of people who were interviewed.

AQ scores indicated a high level of autistic traits within the group (mean=39.0, s.d.=7.0). In terms of gender there were 8 women and 15 men. Regarding employment status, there were 4 people in fulltime education, 9 who had a job, the remaining 10 being neither in work nor fulltime education.

The distribution of ages within the sample is shown in Figure 22, and was such that a wide range was represented.

In terms of their residential status, 11 of the interviewees were living with family, 10 were living alone, whilst one person was living in university accommodation and one in supported accommodation. With respect to marital

status, 16 people were single (never married), 4 were married and 3 were divorced or separated.

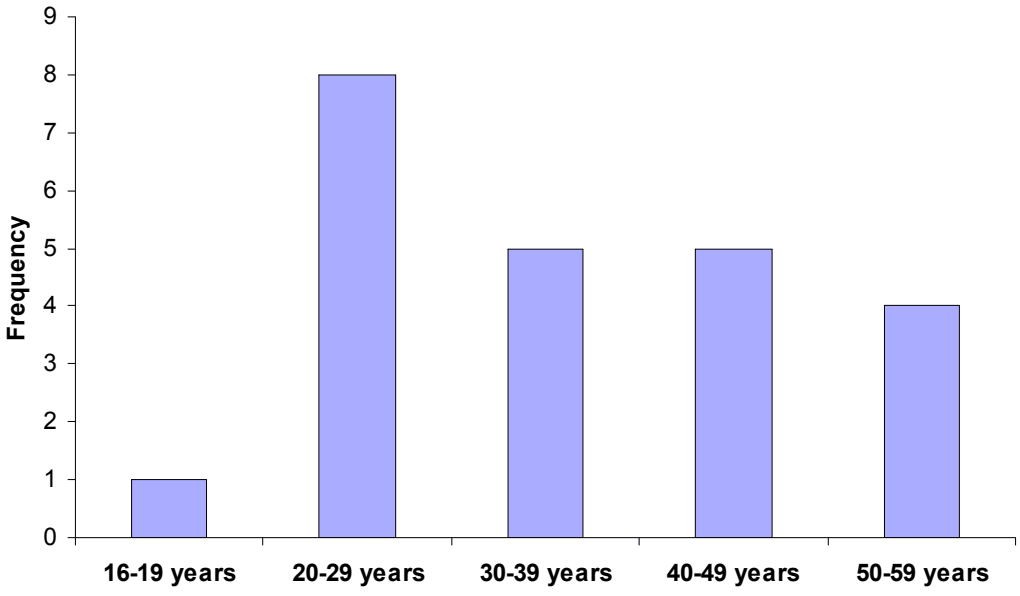


Figure 22. Distribution of ages of the interviewees

The distribution of contact with friends is shown in Figure 23 and a wide range of social contact was evident within the group, with a large proportion having such contact once a month or less.

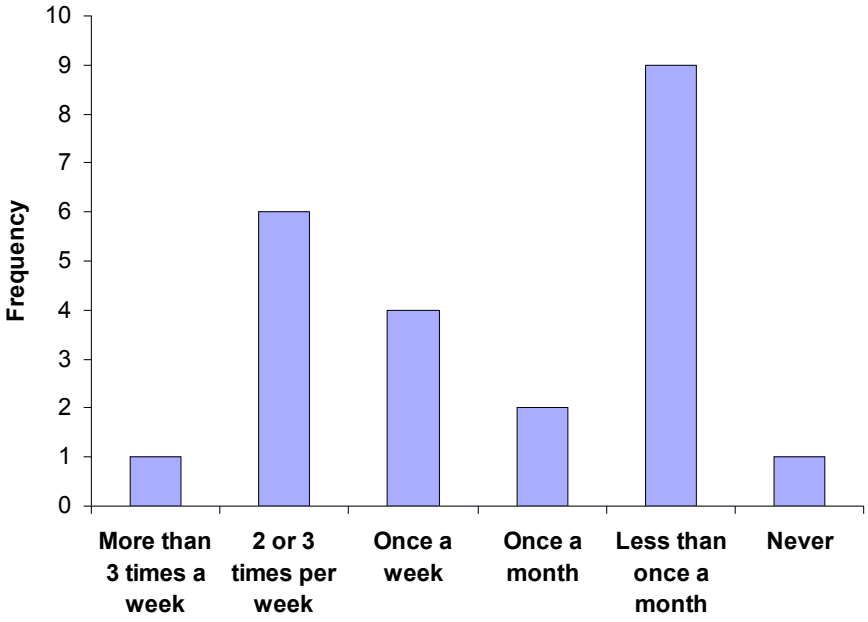


Figure 23. Level of contact with friends of the interviewees

A range of different options were represented in terms of place of Internet access. 18 people used the Internet at home, 8 accessed it at a public library, 7 at work and 6 at college or university. There was a range of time spent per week using the Internet to communicate from less than one hour per week to over 30 hours as shown in Figure 24. 12 people took part in chat rooms, 5 of which on a frequent basis, whilst there were 16 people who exchanged email with online groups, of which 9 did so frequently. A large number of the interviewees (14) said they would miss communicating over the Internet as shown in Figure 25.

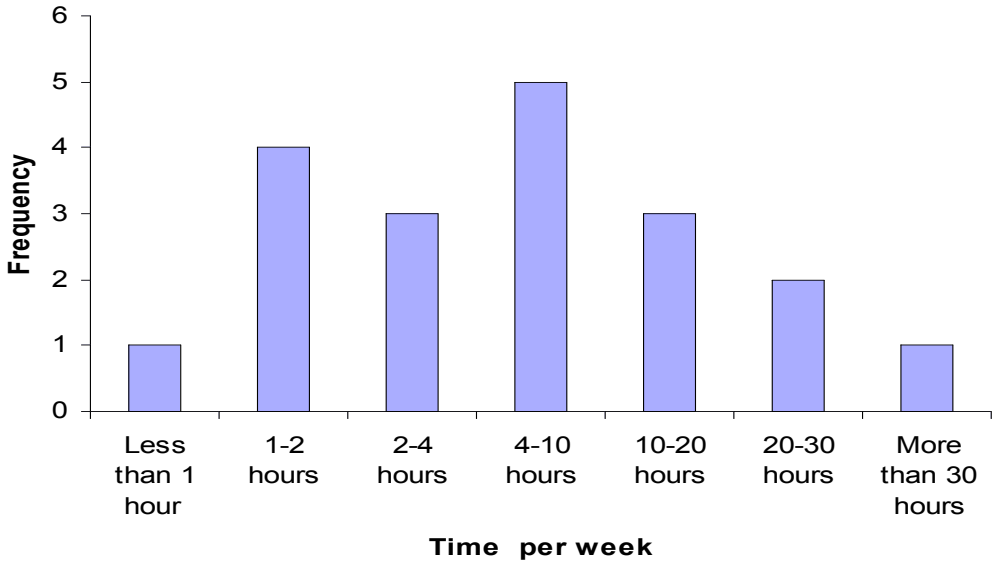


Figure 24. Distribution of time spent communicating over the Internet by the interviewees

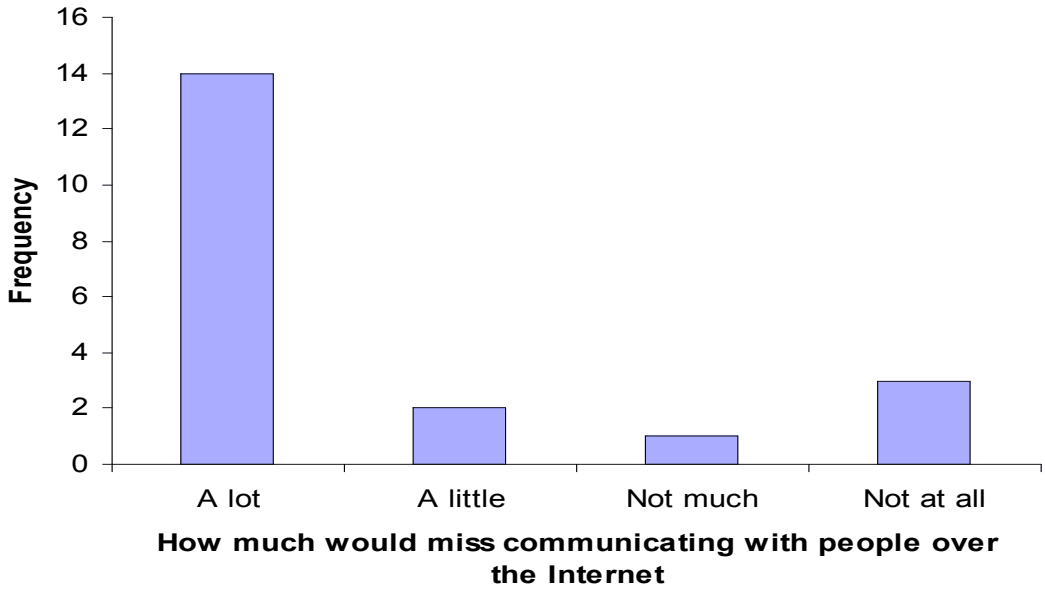


Figure 25. Value attached to CMC by the interviewees

To sum up, a wide range of personal demographic characteristics were represented within the group of interviewees, and attempts were made to represent non or reluctant users within the sample. However the distribution of time spent communicating over the Internet, as well as the attitudes toward CMC expressed in the survey suggest that the interviewees were mostly generally well motivated in their use of Internet-based communication.

Overview of analysis

I shall now present the themes emergent from analysis of the interview data as represented by Figure 26. Central to the analysis is a theme of the interviewee as observer, a perspective from which interviewees offered their analysis of the complex process of communication, online and offline as they experienced it but also with some degree of detachment from "the mainstream."

The sub themes of analysis can be conceptualised as falling into three categories: insights into communication; liberation; and the Internet as a unique form of communication.

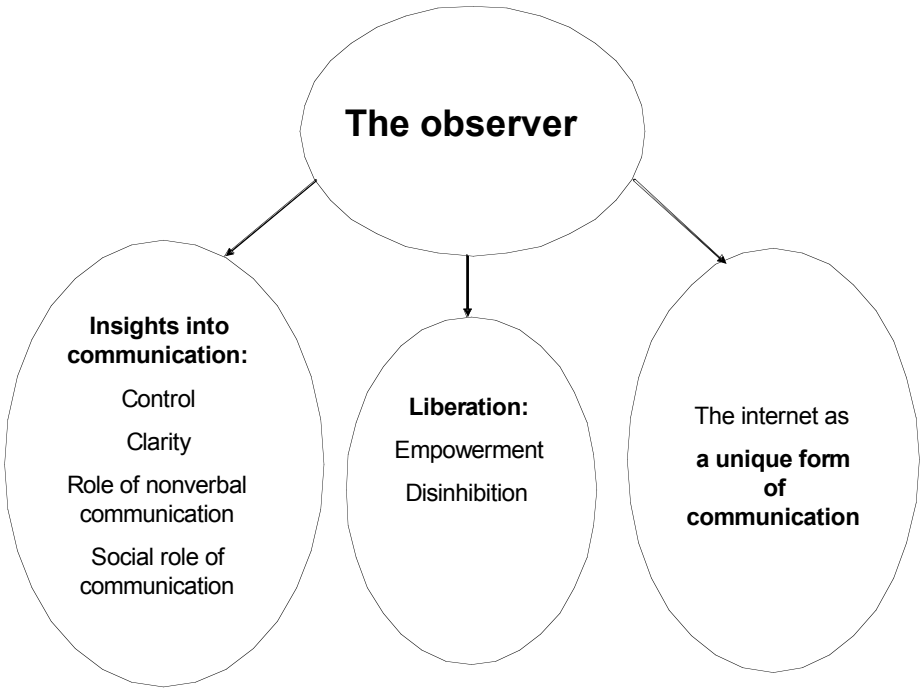


Figure 26. Overview of analysis: a diagrammatic representation

The insights into communication fell in to four areas:

- **Control**
- **Clarity**
- **The role of nonverbal communication**
- **The social role of communication**

Additionally there was a sense of liberation that could come with online communication for people with ASD. This could be empowering and/or it could be disinhibiting:

- **Liberation and empowerment**
- **Liberation and disinhibition**

Finally the insights of the participants highlighted key aspects of Internet-based communication in relation to their own needs, one's which made it:

- **A unique form of communication**

The following sections describe the themes, using extracts from the interviews to illustrate and support the interpretations made in their derivation. These extracts have not been edited in terms of the original content, grammar and spelling, as the idiosyncrasies which some contain were not felt to impair clarity, and altering them may compromise their interpretation. Pseudonyms have been used and distinctive information excluded to protect the identities of the interviewees.

The observer

Many of the interviewees showed a heightened awareness of communication, how it works in terms of its component parts and how it breaks down for them. As well as this they also used their analytical skills to define online communication as they observed it, yielding key aspects of the Internet in relation to their own needs.

These insights emerged from an observer perspective, from people who are detached to some degree from mainstream interaction, feeling perhaps like outsiders as illustrated by these extracts:

> *It is not that I am anti-social, it is that I cannot properly integrate into the everyday norm.* (George)

> *I find it sometimes difficult to make friends face-to-face because the vast majority of people don't understand autism/AS and find me rather weird and even scary…*
> *However, because I feel somewhat isolated from other people, even my close family to some extent, I don't feel any real sense of belonging to any place or group of people.* (Jane)

> *Speaking to some autistic people is like meeting a yogi sage in the hills of peru. We are not from the now. We seem to be very much from the then.* (Paul)

> *My REAL communication alienates me from Normal people.* (Mike)

Associated with the feeling of being outside the norm, was a motivation to try and fit in:

> *I feel the need to fit in with the world and the way it does things.* (Mike)

> *That means for me with AS that I have to try to fit in with everybody else to some extent, I have to be polite to people if I can (that can be a problem as I do tend to say what I think!), and I have to try to interpret body language, facial expressions, tone of voice etc. It can be very stressful.* (Jane)

The detached observer perspective may also create a sense of frustration, bafflement, or fascination at the behaviour or interactions of others:

> *I am also amazed and frustrated by the way many people seem to be able to spend hours saying very little and laughing at remarks that to my mind are simply silly.*

In addition to the above, for reasons totally beyond my comprehension, I frequently find myself facing open hostility, which combined with everything else, discourages me from mixing with people when I can avoid it. (Will)

I'm still stuck in the dream world of a child. The things that people talk about who are in my demographic have different ideas to me. (Paul)

Don't mind direct eye contact if there's not too much of it and it's gentle, if I can look at someone without them eyeing me too often than that is ideal! Intense looks will be avoided but don't necessarily want to get out of the room - it's just too intense…
Actually faces can be fascinating - can't remember his name but there was an exhibition a couple of yrs ago by an American artist who videos actors alone or in groups going through very extreme emotional states and then plays them back in slo-mo in darkened rooms. They're very beautiful and you can look at with with an intensity that is nto generally accepted day to day! (Tessa)

Control

One's success as a communicator depends on how much control one can exert over the interaction. Communication is a complex process and there are many interconnecting levels at which control can be lost. As one interviewee commented:

Communicating is like your first driving lesson; so many things to do and it all feels so unnatural and like you'll never manage to do all of these things together (Simon)

Online communication can restore some control to the process of communicating with other people in various ways:

- **One's own emotional responses**
- **How others may react to what you say**
- **How one is perceived**
- **The structure of the conversation**
- **The ability to get thoughts into words**
- **Processing communication from others**
- **Dealing with too many stimuli simultaneously**
- **Ones availability to others**

- **Dealing with the stress of spoken communication**

One's own emotional response

As illustrated by the quote below, it can be hard for people with HFA/AS to modify their emotional responses:

> *…some people, such as myself, can find it insulting if someone says something unpleasant about something they have an obsession with. With face-to-face communication, the person disagreeing would find the AS patient an aggressive type of person. Typically it is not possible to control the initial reaction. The beauty of online communication is the fact that one may read over the post before making it, read the email before sending it, and press delete. There is usually an 'edit' option on message boards so if a message is sent and the person feels they have been too aggressive/obsessive then they may edit it.* (Sarah)

Sarah's quote, also raises the potential of online communication to provide the time and facility to consider and temper one's response such that a confrontation may be avoided. A "cooling off" period is more feasible online as Will points out:

> *If I receive an email, the contents of which I anticipate I won't like, I can leave it until I'm in the right frame of mind for dealing with it. Sometimes when I don't anticipate an adverse comment or reaction, I can still give myself time to get over my initial rage and still give an honest, but measured response.I unfortunately possess a rather bellicose personality and in a face-to-faceor telephone confrontation my immediate displeasure is likely to be obvious; experience has taught me that once I lose control I usually can't recover that situation.* (Will)

For some their difficulties were such that it was difficult to express themselves verbally when they were experiencing strong emotions. Online communication provided an easier medium to express themselves at such times:

> *When I am emotional, either negative or positive, my feelings are so vast and all encompassing it becomes highly difficult to convert them into language to communicate on to someone else.* (Nicola)

> *If I am upset and need to talk to someone, online communication is better for me to cope with than face to face or using the telephone. With face to face, you have to deal with body language and tone of voice and with the telephone you have to deal with tone of voice.* (Claire)

For some there were also certain online situations in which Internet communication could diminish the likelihood of becoming upset. When talking about rules and moderation in online groups David said:

> *This is particularly important to me because my Asperger's Syndrome causes me to get disproportionately upset when people post offensive or abusive replies to my posts as once happened on an unmoderated* ***xxxx*** *message board.* (David)

How others may react to what you say

Several of the interviewees referred to instances where they had unintentionally upset people, or an awareness that others found them too direct in their manner of communication. To some extent communicating online provided more space in which to consider the impact of what one says on the feelings of the other person, as well as distance from the emotional responses of others:

> *…having been told (and continue to be told now and again) that I am 'direct' 'I know where I am with you' etc. do sometimes spend ages trying to soften up something that could quite happily exist in a few direct sentences except the individual you are sending it to is "sensitive". In this sense e-mail is great as you have time to go over and tinker. Emoticons useful in this context, but perhaps too flippant for some people.*(Tessa)

> *I don't want to upset people but I always manage to say something that's considered awful! At work I have had difficulties because I tend to say what I think, and inevitably find that managers don't like that - which is one of the reasons why I feel that I shall probably be sacked before too much longer.*
> *On-line it is easier, I think, because I can just focus on what is said. As I don't generally meet the people that I am communicating with, I don't have to worry about trying to interpret physical signs, and if I upset someone accidentally, it doesn't really matter to me, although I do appreciate that it does matter to the other person. Clearly it is less likely that I will do that online as I have more time to consider what I am writing, especially that I've now learnt to wait before responding to an emotionally charged email.* (Jane)

Also when the discussion gets heated I won't have an angry or upset person standing in front of me, that would be very hard to deal with for me. (Julie)

However for some it was still possible to say the wrong thing and upset others online, particularly neurotypical people, as David explained when comparing his experiences with online friends who had AS with those who did not:

The first thing I found when I joined the group was that the other members of the group understood me in a way that most of my on line buddies without AS don't. They understood why certain things cause me so much upset and they are also more tolerant of my idiosyncrasies that come with AS. I've often inadvertently upset some of my on line buddies without AS by saying the wrong thing because they don't realise that it is a result of AS until I explain it to them. (David)

Within online groups rules and moderation were a means by which instances of unintended social transgressions might be prevented as Sarah explains with some reservation about the impact on self-expression:

Rules and moderation are useful, particularly for someone with AS, since certain people are affected by the condition in the respect that they will unintentionally offend someone. With moderation, the message can be deleted, and the insulting of another person is avoided. This differs from an offline setting in the sense that when a person has offended someone, when someone has passed a comment, no simple action such as selecting a button (for example 'delete') will resolve the problem. However, it could be argued that freedom of speech is impaired and so it is a contested issue. (Sarah)

How one is perceived

For many there was a feeling that the way in which they came across offline was not how they would desire to be perceived, and that it was easier online to transmit a more favourable image of oneself:

…perhaps the self I express online is more what I would like to be, whereas I am constantly aware of the need to protect myself offline.In 3D I feel isolated and out of contact with people, because of the AS communication difficulties. I come across as stand-offish or cold. That is not how I want to be, and perhaps I am compensating in my online persona. (Tom)

For some it was the purely textual nature of online communication which was seen as conducive to conveying a more positive impression:

> *I think that the 'first impressions' that we give off can be less worrying when it is all down to textual communication* (Andrew)
>
> *Only my words are judged, not my behaviour.* (Jane)

Additionally it seemed the simpler mode of communication online, as well as the different pace of interaction, created a more comfortable space in which to consider how one may be perceived:

> *I think I'd be more inclined to consider what other people might be thinking while I'm on-line than I would in any other medium of communication, simply because I have so much more freedom to think, and less to think about all at once. Normally I'd have so much to worry about in terms of how I'm coming across, that considering others would be the last thing on my mind.* (Ian)
>
> *I did have a valid point but I came across aggressively rather than assertively. This is a recurrent problem in the real world and consequently I am looking into doing an assertiveness training course where I will be taught how to be assertive without being aggressive. While I am finding this rather difficult in the real world, I find that when talking on line it is much easier to be assertive without being aggressive, probably because I am in a more relaxed environment and can take more time to think about what I want to say to the other person.* (David)

The structure of the conversation

Another way in which many interviewees experienced a lack of control related to a struggle with conversational aspects such as pace, topic and the timing of turntaking, particularly in a group situation, as vividly explained by Mike:

> *In a group situation I face some strange problems, mainly due to knowing WHEN to say something and WHAT to say. I normally just but straight in with what I want to say. I never feel part of the conversation. I am more of an outside observer. Its like watching the TV and then shouting at the TV some comment as if talking to the actors. I tend to concentrate on the Subject of the conversation NOT who is talking. So as soon as I have something to say ALL I can think about is saying it. I can not listen in detail to anything else being said. I need to get the*

thing I wanted to say out of my system .I can not simply forget it either. It just HAS to be said. Also I find it hard knowing WHAT to say. Well I always have something to say but too many times I am stuck on the 1st topic and can't move onto the new topic UNTIL I have said ALL I need to say on the 1st topic. ALWAYS this bores the people and they then socially exclude me from the conversations. - reinforcing my observer status. (Mike)

Online however there is a sense of having more control over these aspects, and hence more of a voice:

You can take as much time as you like - ie not under pressure You have total control (my favorite) - the conversation goes where you want, often people will move it away too soon or once moved be reluctant to go back as though it was all finished. I'm not known for my lightning intellect - only once things have had a chance to sink in and gell a bit can come out with a thought out response - people rate speed of reply as quality - no speed no voice (Tessa)

When chatting in a chat room, I don't have to wait until someone has finished speaking, so therefore, I don't ever interrupt. Sometimes I but into a face to face conversation because I don't always know when someone has finished speaking. (Claire)

The ability to get thoughts into words

There were many references to the difficulty and frustration experienced at not being able to put thoughts into words in spoken communication situations and the effect which communicating online could have in enabling one to regain some control over self-expression:

…if I'm faced with more than one person I become pretty non-communicative. I can feel my tone of voice switching to monotone and I really struggle to get my true thoughts out and can feel my personality being suppressed. Just reading back through this email, in my head I can imagine the inflections and tone of the message all being in the right places to convey my meaning in the way it is intended. (Nicola)

I feel that when i am typing directly to a person I can imagine them listening to me. It helps me express my thoughts. If I was face to face with the same person I would not be able to express my self. I would not be able to come up with the words that I need to say. (Mike)

Whilst my thinking process is clear and logical (as is proven by my evident understanding of mathematics, science and engineering), it is not a verbal process; consequently I have difficulty putting my thoughts into words. I was probably well into my thirties before I was able to frame a logical argument in real time…..

Emails have all of the advantages of letters, they give me time to think about what I want to communicate; they allow me to dump my thoughts and then rearrange them (Will)

Processing communication from others

Losing control over a communicative interaction can also relate to problems processing incoming information from other speakers, which can be addressed by the permanent and slower nature of online communication:

In my experience people with AS are all plain speakers - we say exactly as we find and are not naturally tactful, nor mindful of conversing in a socially acceptable manner. Also I definitely fall victim to the 'black and white' thought patterns that are noted in people with AS which sometimes results in 'knee jerk' reactions to something that may be said in conversation because I haven't really considered the bigger picture of the topic in handBasically what I am trying to explain (in a rather round about way, I'm sure) is that often I will miss the point that someone is trying to make, or I will read into it something that wasn't intended and then respond accordingly. Then after enough time has passed that the correct information has finally filtered through into my comprehension, I realise my mistake and wish I could have 'got it' in the first place and given a fully informed response based more in reality than whatever response I came out with at the time. So you see, people that talk to me are likely to see such outbursts of random talk from time to time, which I guess they must think I'm odd, or maybe a bit dumb (which makes me very self conscious, as I know that I'm not stupid) but unfortunately in 'real time' you cant take back what's said and done. Whereas the time delay in sending electronic messages, allows my brain the time it needs to comprehend the situation. Then when I read my own message back to myself I can often see whether I've got the wrong end of the stick or not, and correct myself before making an idiot of myself again. (Nicola)

As Nicola also points out, taking one's time to process information is achieved in a more acceptable way online:

First off, being online eradicates all those 'awkward silences' you'd have in conversation due to (in my case) needing time to comprehend exactly what somebody means before responding. (Nicola)

Dealing with too many stimuli simultaneously

For many spoken communication could be overwhelming due to sensory overload or difficulties dealing with too many stimuli simultaneously. This overload was affected by extraneous sensory stimuli as well as the stimuli involved in communication, and was particularly problematical in group situations:

Assemblies of more than four simply become too complicated and if several people are talking at once I find it difficult to filter out the voices. The sensation of being surrounded by a lot of noise amongst which I comprehend only the odd word is horrid. I probably appear rude in these situations, because I have to either continually ask the person that I'm speaking to, to repeat what they're saying or I simply nod in the hope that they think that I understand them.(Will)

Seeing you face to face would be distracting. (don't take that personally as a negative on you) The room where the interview would take place would be distracting. I would be worried about getting back, what time train do i need to catch. I would be looking around the room to try and be interested in the things around me. (Andrew)

Paul also describes the overwhelming and confusing nature of the telephone from his point of view:

Sometimes there are so many things i must take into account i feel lost. Too much data, and also bad delivery….

Also just having one ear piece i find problematic. My ears process data at their own rate. Not "mine". So someone talking in one ear and background noise coming through the pther can be really confusing. Sometimes i feel like someone is pouring honey into my mind when i'm on the phone. it can be alleviated by ensuring i am totally focused to "the phone". Conjugate with this is sound quality. Most people voices at least have the same source. The biogenic loudspeaker. The mouth. But phones can use any number of different ear peices and mike combinations. So the original sound can be nothing like the final sound. Also the material of the phone can add its own resonance to the whole affair. So i would say that most of my issues regarding the phone are to

do with bimodal aspects and my lack of ability to multi task smoothly. To make that worse there are sonic dynamical issues. What a pain in the ass i must be. ha. (Paul)

The loss of control due to sensory overload may be alleviated by online communication:

Also when chatting in a chat room, I don't hear lots of people talking at once. There is no noise at all. When talking to someone in a room full of people, I also hear lots of other people all talking at once. It just sounds like a noisy babble. I am not able to tune this out, so I have to really concentrate on what the other person is saying which is very tiring for me after a little while. (Claire)

…and we have more time to try to make sense of the other person rather than being rushed and bombarded by lots of different sensory information in real time. (Andrew)

Staring at the screen I concentrate only on the words being said to me and the words I am about to send back. (Mike)

However there is still potential for interference to online communication, for example in places of access which are more public, as Paul explains:

I find the internet very accesible, easy to use and i dont suffer from anger at all where computers are cioncerned. However, as you will understand?, the environment is equally important. So my preferences are different to somebody elses. Having someone making noise or just messing about near can be very difficult for me. I have left the library before because some people do not adhere to the very few rules extant in a library. So environment is for me personally the make or break of communicating with somebody. (Paul)

Ones availability to others

Unanticipated face-to-face or telephone communication could be intrusive, disruptive and difficult to deal with:

The thing I don't like is when somebody suddenly shows up and starts asking about something they have requested - chances are when they arrive I'm busy with something else and I often cant switch my brain over to work out what it is they are asking about. Cos I'll be kinda 'walled in' to the task I'm doing and cant remember anything else. (Nicola)

I hate it when I'm doing something and someone else suddenly wants to speak to me; it derails my train of thought terribly. I don't want to be that available to people. I like to be in control of when I deal with them. (Pat)

I hate answering the telephone as I have to provide a response the moment I am asked. I am put on the spot and this makes me nervous. I am not able to think properly about the answer I SHOULD be giving and tend to answer with the answer on my mind. (Mike)

Online communication for many of the interviewees conferred more control over one's availability to others:

If I'm stressed and need to limit communication, I can avoid checking the email for a few days, so that I don't even know if there ARE any emails waiting: whereas you can tell if there are letters on the mat, or faxes arriving, or messages flashing on the answering machine. I can think about and prepare my reply in the middle of the night, when it's quiet and no one's bothering me. (Pat)

The final and one of the best benefits of online communities is that when I simply don't feel like chatting, I can switch off! Nobody can infiltrate my space unless I allow them to so I'll never have to put up with pointless comments such as 'cheer up love it might not happen' on days when I simply don't feel sociable. (Nicola)

Dealing with the stress of spoken communication

Associated with their difficulties at various levels of spoken communication people with AS/HFA can feel overwhelmed, stressed, anxious or threatened when speaking to other people, which adds to the loss of control.

I suppose that one of the greatest differences is that offline, one is generally physically involved with a group of some kind, like living in a village, for instance. That means for me with AS that I have to try to fit in with everybody else to some extent, I have to be polite to people if I can (that can be a problem as I do tend to say what I think!), and I have to try to interpret body language, facial expressions, tone of voice etc. It can be very stressful. Like many other people with autism I spend my life in a more-or-less constant state of anxiety or fear and so involvement with any kind of off-line community is usually difficult,

especially at the beginning when I'm having to meet new people and be in different environments to one's I know. (Jane)

Some described the physical response experienced in the presence of others, for example:

There's an energy to being physically in another persons presence whether you know them or not. It can be energizing or draining, it's rarely neutral. (Tessa)

Mike experienced somewhat acute and specific physiological symptoms in confrontation situations:

Also when arguing I am affected Physically. I end up with a stutter (which never exists at any other time) my breathing is affected and My heart beat changes. I feel all weak and shaky after. (Mike)

For many people there is relief online from these overwhelming emotions:

> *use of e-mail, MSN and suchlike are indispensible to the aggrandisment of my social life and learning, (allegedly) being more readily available and less threatening than perslnal contact.* (Robert)
>
> *Internet is calmer, less stressful, less energy draining.* (Tessa)
>
> *Also, while I still have to exert some energy into my work, it is not quite as stressful as trying to muddle my way through social encounters. Internet communication therefore takes away much of the frustration and incomprehension I experience with face to face encounters.* (Alison)

Clarity

There was a concern and struggle with the fact that people are not always precise and accurate in what they say and how they say it, and this is associated with a tendency toward literal interpretation:

> *The thinking processes of others also present me with difficulties in two ways: their imprecise use of language, for instance 'he screamed at me', 'it does my head in' and the word 'love' appears to have a multitude of meanings; their acceptance of 'socially accepted' opinions, which fly in the face of logic, for instance I cannot differentiate between 'faith' and 'superstition', why is it more reasonable to believe in 'Allah' than in 'flying saucers' when there is probably slightly more evidence for the existence of the later..* (Will)

Social chit chat was also a source of difficulty, as illustrated by these two excerpts:

> *I also have difficulty in understanding the role of chit-chat like "How are you?" which apparently means "Hello".* (Jane)
>
> *I'm not a person who chatters for the sake of it, and where gossip is concerned, i may as well be considered as the anti-christ no less. I get irritable if people ask me things like "what have you been doing " " how are you?" both open ended and none of your business. I know it sounds horrid, but this is how i am.* (Paul)

There was a feeling that the Internet lends itself to more considered and clearer communication, as these two extracts from the interview with Claire imply:

Also as I can misinterpret communication because people don't always say what they mean verbally, email gives people a chance to explain to me what they really mean. This then saves me from getting upset. …when people are using written communication, they have more time to think about what they really mean. (Claire)

There was also the view that when communicating online people are less likely to waffle or engage in small talk, and more apt to come to the point:

I think many interactions are easier done via e-mail - people are more likely to come to the point (Tessa)

Generally there is less waffle with written messages and so with any luck I have more chance of understanding people and feel much more equal to them. (Jane)

The availability of a permanent record online also supports the potential for accurate and efficient communication. When comparing spoken communication to online communication Will said:

A further problem with spoken communication is the a lack of a record, resulting in the possibility (if not probability) of your being misquoted, together with the likelihood of forgetting what you have been told and being too embarrassed to ask again (It's not always possible to take notes). (Will)

The absence of visible signs of listener response means that this influence over what is being communicated is removed, as Will reflected:

The anonymity of the communication medium helps me to be honest with you. To a limited extent I've had to learn how to adjust what I'm saying to people's reaction to what I've said. If a line of argument seems to be producing a hostile response I try, with a certain amount of resentment, to adjust my argument to bring it more into line with what I deduce the recipient wants to hear. (Will)

However due to literal interpretation, breakdowns in communication are still feasible online, despite extra time available to process what is said, as indicated by these two quotes:

Thinking about what I wrote earlier about having time with e-mails to think things over and write what you mean etc. That said recently got an e-mail form a friend re meeting up at a friend of hers who was doing a clothing sale to raise dosh for something and it had the word dress in it.

So I duly turned up with some dresses which have been sitting in my cuboard because I never wear them etc. Everyone else turned up with shirt, jumpers, trousers, jackets as well as dresses and I had in the process of clearing out dresses also sorted out that kind of stuff but because the e-mail said dress left them to one side to take to a charity shop instead. So having time to read doesn't necessarily mean I really think. TO me that's a classic me taking things literally. (Tessa)

However I take things literally too often so I may look at the email too closely than is needed and read far too much into it. (Mike)

There was also concern about the potential deterioration in English used online, with detrimental effects on clarity:

As you know I like emails, but they are partially responsible for an appalling decline in the standard of English used in all forms of communication. With sloppy English comes a decline in clarity, which in turn, because it means that more things will go wrong, must have an adverse affect on every aspect of our lives. This is my opinion at least! (Will)

The role of nonverbal communication

The absence of nonverbal communication online was mentioned by many of the interviewees as a way in which the struggle of communication was lessened. The lack of such cues could relieve the burden in terms of processing as well as expressive skills as the following quotes illustrate:

It means I don't have to worry about the body language or the facial expressions of either myself or the person I'm talking to. I don't have to think about what I should be doing/showing, or what visual cues and signals I should be responding to. That leaves me with more time to think about what I'm being told and what I want to say in response. (Ian)

I don't need to worry about my body language, e.g. eye contact, body posture, tone of voice. I often find that during face to face conversations I have serious difficulty giving out and reading the correct signals whereas in online communication this is not an issue. (David)

I feel as though my real life is on the computer, because it is from there that I am able to communicate more successfully, with so many of the social world's obstacles removed: eg inability to read peoples' faces. It is

considerably less painful than having the social interaction of the real world (Alison)

However there was a recognition that nonverbal communication is an important part of communication. Some felt they had learnt to be consciously aware of it, as Tom explained:

Some Aspies are unable to make eye contact. I did not do so, but after I was diagnosed and started to learn about the Spectrum I read about body language and eye contact. I have trained myself to do eye contact, although I don't always gauge it right. Aspies are by nature blind to non verbal communication, but I have found that it has been possible to train myself so that I can give appropriate signals, and read the other person's. (To an extent, and as long as I remember to do so.) (Tom)

For others, dealing with nonverbal communication was felt to be more intuitive:

But it's not so much the face that gives info though I do tend to stare at people - trying to pick up more than is coming from they're speech - it's more their physical presence than the face - ie the vibe they give off. (Tessa)

A great discomfort with telephones was reported by many, and this was attributed to the lack of visual cues in a real time communication situation, cues which could support difficulties processing auditory stimuli and add supplementary information, particularly with respect to conversational turn taking.

> You mentioned that on the telephone you don't know when it's your >turn to speak or listen. Is this something which is easier in a face to >face situation, and if so why do you think that is?
It is easier in a face to face situation, because I can see their facial expressions and body language, so I can see when they want to talk or listen. (Julie)

One other thing - it's often harder to tell when it's my turn to speak, as there are no visual cues. Admittedly, I find it harder to read visual cues in a face-to-face situation than those without Asperger's, but it's a damn sight easier to read them when they exist than when they don't! (Ian)

Telephone is the worst *- it's in real time, plus you have to rely on voice alone. (I suppose videoconferencing would be a* bit *better, I've never*

tried it. There'd probably still be slight voice and face distortion.) If I have to have a real-time conversation, I prefer face to face, because you can see the lips move. (Pat)

So it seems that many of the interviewees felt that they gained something from nonverbal communication. However as can be seen from the quote below, being able to integrate this knowledge with other aspects involved in the complex process of communication is problematic, hence the lack of nonverbal cues online being seen as beneficial by many of the interviewees.

On the one hand, I have visual clues with a physical encounter, but then they could overwhelm and confuse me, if I found too much detail to absorb. (Alison)

Whilst there was a strong sense of benefit from the lack of necessity to deal with nonverbal communication online, as with many situations in life there are trade offs. The use of text limits the potential to communicate aspects of tone such as mood and humour:

…it can be even harder to know what people are really feeling, because, although I think I pick up on far fewer signals from facial expressions etc., I wouldn't go so far as to say that I don't gain anything from that part of face to face communication. Similarly, tones and volumes of voices. (Andrew)

I suppose the biggest drawback is difficulty communicating subtleties that in everyday conversation could be conveyed by tone of voice, gestures, facial expressions, that sort of thing. It can be hard to tell when someone is joking or make it clear that you yourself are joking. (Craig)

The loss of visual information and different timing online for some diminishes the potential of the Internet as an effective interactive mode of communication such that ambiguities or misunderstandings could happen online and additionally these could be difficult to address without immediate visual feedback. This was strongly expressed by Simon:

Face-to-face communication involves very obvious anger signals, and checking of whether you've understood somebody. Also ridiculing what someone has said if you strongly disagree with it ("Oh now really . . ." &c.). If the person you're speaking to does any of these things, you can check what they have understood at the point where a misunderstanding

may have happened and is thus more easily identified and corrected. If they think through your e-mail, come up with a cogent reply and you then interpret that reply based on your intention (rather than what they understood you to mean), then it becomes very difficult to find where the misunderstanding lies. (Simon)

The social role of communication

For some of the interviewees face-to-face social contact was seen as the norm, something they aspired to and desired but which was hampered by communication difficulties to varying degrees. Others differentiated their own needs in terms of the amount and purpose of their contact with other people, being less concerned with social interaction for its own sake and more concerned with functional activities. This is illustrated by two extracts from Tessa's interview:

When I was younger (much younger) my dislike of socializing used to stress me out and did try to join in etc but found it essentially futile and self defeating to spend so much enegy not being myself. Much later when diagnosed felt alot of relief and alot better about simply carrying on being me. Some aspies do want more contact with people and the difficulties around understanding how social interactions work makes this hard and can stress them out. In my case I have chosen to limit my interactions and this works well. (Tesa)

…have to say that I much prefer doing things with people that talking. Unless the talking is mixed with the doing ie this morning went swimming and met a regular small bunch of people and we chat a bit in between sets, usually about swimming..(Tessa)

This difference in desire for social contact seemed, for some of the interviewees, to be a reaction or adjustment to their struggle with face-to-face interaction as suggested by these two extracts:

Also, the nature of my disability is such that I do not particularly miss social encounters, with all the pain they can cause. I am currently having counselling from a lady who is not Asperger's and I think I could live quite happily without these meetings, as they hurt me so much. (Alison)

I dont hold relationships too well, so keeping in touch with people is so hit and miss.

For my own benefit i keep friends to an absolute minimum and also keep family at very long arms length. I dont understand a lot of what goes on within these arenas. mainly the social aspect. (Paul)

However for others perhaps there is a more fundamental difference in terms of need, as implied in this comment from Will:

Since I've been helping with your project I've discussed the ideas with several of my acquaintances who all seem to prefer more personal forms of communication than I feel comfortable with. There are times when I feel the need for company and to an extent need people, but my need seems less than that of others, and I therefore welcome the anonymity of emails. (Will)

For those who have different needs in terms of the amount and purpose of social interaction the Internet provides opportunities to gain and maintain contact with others without the stress and strain of face-to-face interaction, as Tessa comments "*It's a way of keeping in touch without being full on.*"

The following excerpts illustrate how some of the interviewees were incorporating online communication into their lives as a means of social interaction, appropriate to their needs:

I would say that online communication has increased my social contact and reduced the possibility of feeling lonely. I don't need to have face-to-face communication to feel that I have social contact. (Jane)

Emails have had an entirely positive effect on my relationships in that I lose contact with friends and acquaintances less quickly. Emails substitute for telephone calls, which I have a great reluctance to make and if I'm to meet anyone it has to be arranged. I'm usually blown out eventually by my lesser reluctance to meet anyone at all. (Will)

IPersonally find it's easier to be part of a community if it's not too intense ie online rather than in person. I do believe that a great many groups in person are quite rigid in what behaviour is expected of you - when I write behaviour that can of course be of any sort "good" 'bad" whatever - the key thing is to be a "part' of this you have to either lead or conform and usually they need to see alot of you - having your own life is frowned apon. I'm definitely not a leader - would make an excellent dictator though! As to following - couldn't if I tried - not for any

length - have to stop and ask why - that's not to say I'm not a creature of habit and probably follow along loads or 'norms' of what's expected in society as well as my own unquestioned by me norms but being in a group of people is a dynamic alive thing that doesn't come naturally.. (Tessa)

The Internet may also enable them to find and contact others with a shared interest such that any face-to-face social contact can be focussed around an activity or purpose as would be their preference:

Am on a **xxx** *forum and from that have met up with others at races which was fun and will meet up again at a training camp next April. There are social gatherings organised on the* **xxx** *forum but I choose not to go to these - they have no appeal - do not like hanging around with people at all - no meeting up for the sake of it. For me this is fine and normal - suspect that I'm just chronically antisocial - it's not a crime. Am not seeking to meet people to be with people. It may sound ruthless but it's not for me.* (Tessa)

Emails and web pages provide an essential media for exchanging information with my many acquaintances, fellow **xxx***ers,* **xxx***ers,* **xxx** *enthusiasts etc. These communications often lead to face-to-face meetings, where I'm happy undertaking joint activities with them and enjoy meeting them, but if things start to develop into a social event I soon find myself looking for an excuse to leave. I often plead my, quite genuine, discomfort in crowds as an excuse to leave immediately after an activity has finished. The vast majority of my emails fall into this category.* (Will)

For those who desire social contact for its own sake, the Internet has beneficial potential. One can shop around for new contacts, find people with whom it is easier to interact, perhaps people with whom there is common ground improving the chances of a positive relationship. It seemed to be a more comfortable and reliable way of going about finding others with a common interest, and establishing communication with them:

It would appear to be the simplest, most convenient way to meet people with the same interests, particularly since the alternative would appear to be related to speaking to strangers you are connected to only through that interest in an offline setting, which is not a method of meeting people who share my interests I find appropriate……There are

few accurate indicators (again, in my view) of whether or not a person shares the same interest as myself, and I do not wish to humiliate myself by beginning a conversation about my interest, only to discover that they are not of the same opinion (as an example, if a person has developed an interest in a film series, there is no guarantee that the strangers who joined them in the screening share their interest; they may be there through curiosity for instance, not neccessarily because they share the other person's views). To speak to people one does not know is to risk ridicule and abuse; the person one approaches may be unpleasant and tell the other person to leave (impolitely). (Sarah)

One huge advantage is the ability to find like minded people by doing keyword searches on members' directory profiles and through online groups, something almost impossible in the real world. (David)

One of the main benefits of on-line communication is that age is no barrier. If you can't see the person at the other end, they could be my age for all I know. They say "you're only as old as you feel", and this really holds true on-line. People may write like you'd expect a vibrant, youthful 20-year-old to, but could actually be about 50! My best friend on the planet is a 43-year-old married mother of 3! This could simply never happen in "the real world" - if I had any friends I saw regularly(!), they'd all be around my age, and there would probably be at least an equal number of men as women. I seem to get on well with women on-line though - maybe I'm very much in touch with my feminine side when I express myself! (Ian)

Communicating online can eliminate the stress and anxiety of meeting and communicating with people for the first time, such that other people may not be put off by nonverbal signs of autism and both parties may get to know each other more easily:

What makes it easier for me is that through writing I can let a person know who I am without having them thinking that I'm strange, which is what a lot of people think when they meet me for the first time (although this isn't as bad as when I was younger). I always feel awkward and shy when I meet new people for the first time that don't know about autism and might have the wrong ideas about it (like thinking that you're like Rainman or something like that)When I write I can tell them about my autism and sort of ease them into it I guess. (Julie)

…when I'm with my on-line friends in person, I know that they already know all the crucial information about me - the things I'd be far too embarrassed to admit in person, especially upon meeting someone new for the first time - things like the fact I've got Asperger's, and how that affects me. When I'm with someone new in person, or on the phone, I can't just link to some web page about Asperger's so that I don't have to explain it all - I have to tell them in excruciating detail, which is very uncomfortable at the best of times, let alone with a total stranger. But I know my on-line friends will already understand me - they'll know about my little quirks and will accept them - they'll accept me for the way I am, and look past the Asperger's, in a way that strangers knowing nothing about me would not. Like I say, it feels so liberating. And on top of that, I already know a lot about my on-line friends too, prior to meeting them in the flesh. Having got all those worries off my chest already, I can relax in their company as if I'd known them all my life…(Ian)

Actually I think that in many cases I know people better online because their thoughts are written down and I can study them, focussing only on what is written. Face-to-face I'm having to spend most of my energy in understanding what they're saying and trying (unsuccessfully, usually) to get clues from their facial expressions or body language. Quite often, then, I can forget who I've been speaking to afterwards. (Jane)

In some cases new contacts made online may become offline contacts too as illustrated by these two excerpts:

Chat and bulletins are both mediums I have used to make initial contact with people with shared interests - in some cases I have gone on to meet these people in reality and have formed a sound friendship group as a result. (Sarah)

The Internet has had a huge impact on my life since it slowly but surely made its presence felt. Before 1998, I spent much of my spare time playing computer games (something I hardly ever do now that the Internet has taken hold), and watching TV (something I do to a lesser extent now). Okay - I've always had a very narrow range of interests throughout my life (typical Aspie trait!), but it's probably even narrower now than it used to be! On-line communication has improved my social life significantly. Okay - so I have to travel large distances to see on-line friends of mine in person, and I obviously don't get to see as much of

them as I would if they lived at home. But the time I do get to spend with them is time I really enjoy and cherish. (Ian)

However, as can be seen from the extracts below, friendships which remain purely online may also be valued:

I have circles of friends in the real world and circles of friends in cyberspace and both are equally important to me. (David)

Here there are a small number of people whom I have come to know through mutual support. There are also many more who come and go. I have never seen their faces, or heard their voices, but I know more about their lives than many 3D friends, and they of mine. There is open discussion of problems with medications, with abusive family members, and financial woes. There are very few people I know in the flesh with whom I would be willing to be so open, or expect them to be so open with me. I think this is because we are not likely to meet, and because there is the assumption that anything we say will not reach colleagues or friends who are not completely trusted. This is where someone would turn for help if they are feeling suicidal. If I read such a message I feel the obligation of friendship to respond with prayer and words of encouragement. I also feel worried if there is prolonged silence from such a person, especially as I have no other way of making contact. I think that what I am saying is that there are online relationships all the way up to close friends. (Tom)

As well as the potential for finding new sources of friendship, existing relationships may also be enhanced by online communication as these interviewees explained:

…but I would say that the reverse process whereby real world friends become on line friends is more important to me, particularly when the other person also has AS. I find that I, and other people with AS, often feel more comfortable communicating on line than face to face, especially when one needs to discuss issues of a delicate nature. Even aside from that I have always found that my real world friendships are enhanced when we have the added ability to communicate online either by email or by instant messaging. (David)

I like using MSN to talk to a few friends. I feel I can say more then when face to face. I can express myself MUCH better. I am more open and reveal more of my thoughts. If face to face I stick to factual

communications and do not give any feelings. MSN allows me to open up. (Mike)

For many of the interviewees, Internet-based communication had lessened loneliness:

Far from leading to me staying at home all the time sat in front of my PC, being on line at home has actually led to me going out more and meeting more people. It has not only improved my social life in the real world but also given me a second social life in cyberspace and the two frequently cross. (David)

Internet communication has made me far less lonely. Whenever I have problems with my computer, I absolutely hate not receiving e-mail (or not being able to get it from the comfort of my own flat). (Chris)

When I was at University, I think I benefited a lot from email; it made me much less lonely than I think I would otherwise have been. Mostly it was email groups (some of which were AS related, others hobby *related) and I organised the University* **xxx** *society by email, which kept me in contact with others. I think it still makes me less lonely.* (Andrew)

However many expressed the view that online interaction was not a substitute for more personal contact, which was seen as more real with the opportunity to share activities:

I do value online communication because it means that I have access to it at any time. However, I would not want to replace relationships with people in the real world, with online communication.
It is very important to have human contact. I do make sure that I go out and mix socially with people. I do value proper conversations.
I know of some people with Asperger Syndrome that are on theor computers all the time. They don't have any relationships with people in the real world. This is not a good thing. (Claire)

I wouldn't like to withdrow completely from being part of offline communities (especially as my main hobby - ***xxx*** *- is predominantly an offline community although there my be online communities within that offline community). This is because just the thing of seeing people makes it seem less 'artificial' than offline communities.* (Andrew)

However, it can also be a joy to make a trip to se them in person, and be able to do physical activities, rather than just talk nonsense! :-)

(Mind you onlione games may partly substitute that, althou I personally don'yt get involved with that.) It is good to be able to have physical contyact (in some cases), share/consume comestibles, play music, and show off one;s appearance/mannerisms &c! (Not really sure how to clarify that!) (Robert)

The concept of "realness" seemed to relate in part to the degree of interactivity of the communication medium involved and as such online chat was preferable to asynchronous forms of online communication for some, being seen as a better way of getting to know other people:

Unless two people are practically addicted to e-mail(!),that method of communication is predominantly "one-way". On the otherhand, instant messaging and chatting at on-line chat sites is far more "two-way" and interactive. So it follows that the latter method is much more effective when it comes to forming and maintaining friendships. It's more instant (hence the name "instant messaging"!), and you can get to know someone far more quickly than you could ever hope to via e-mail. You can "bounce" off them more, in direct response to each comment, and maybe exchange banter, throwing in emoticons and amusing sound effects if necessary/appropriate. In e-mails, that would be more difficult. (Ian)

I think a conversation involves personal interaction (of the kind Aspies are not good at). Only speech and instant messaging or chat are real time, we are doing quite well with you asking questions and me trying to answer them, but the time lags break it up. (Tom)

There was also a feeling that although there was the possibility for online friendships, those relationships which were pursued offline were potentially more meaningful:

Making friends would appear to be easier online, possibly, again, due to the fact that I am less of an Asperger's patient online than in real life. But, of course, in contrast to this, the quality of friendships would probably be greater in real life. Real life friendships are likely to be more true, since they know the real you, as opposed to the image you portray online. (Sarah)

I suppose that I have to conclude that face-to-face it can be more difficult to make a friend, but when I do, it tends to be close. Online, it is easier to make a "friend" but it is unlikely to be close. (Jane)

Liberation and empowerment

The enhanced control online can have an empowering effect, such that people may interact with others on a more equal basis, as these comments imply:

> *In a face to face conversation it is likely that the other person will be using facial expression and body language to some extent. A written conversation does not exactly compensate for any lack of ability in this area, but it reduces both parties to the same level.* (Tom)

> *I have now been on the Internet for 5 years and in that time it has radically transformed my life for the better…. I now consider it an essential tool which I could not manage without. Far from turning me into a nerd spending all day sat in front of my computer, being on line has led to me going out a lot more and meeting new people. It has touched every single aspect of my life and it doesn't seem possible that I could have managed without it until just 5 years ago.* (David)

> *I think internet communication compensates for difficulties in face-to-face communication because I feel more empowered and in control; a sense that nobody else can take over, while I have sole control of the computer, what I choose to do with the screen and nobody can stop me. So, I suppose it feels quite liberating.* (Alison)

There were various ways in which interviewees may experience this empowerment:

- **Self-expression**
- **Choice over self-presentation**
- **Adoption of a different role**
- **Therapeutic benefit**
- **Feeling protected and secure**
- **Group participation**
- **Demarginalisation**
- **Gaining support**
- **Benefits to offline interactions**
- **Integration in to the workplace**

Self-expression

Many of the interviewees described marked differences in their ability to express themselves online compared to offline:

> *My guess is (although I've never really had this confirmed by anyone) is that a comparison between my emails and an actual 'live' face to face chat, you would probably think I was two different people. Sometimes I really crave a private face to face chat with someone, but then when the opportunity arrives, I find that I haven't got much to say to them anyway, and/or that they do not react/interact in the way I expected them to and things don't flow in the exact manner I had foreseen them to* (Nicola)

> *I am it has been said very wordy when online. I think this means that i have a tendancy to "go on a bit". This is really different to my real world contact. I will be silent if there is nothing for me to get audiable about. So i guess the main difference is output. In the real world i am just as happen to stay silent and non verbal, whereas online i have the advantages we ahve discussed at hand, and so have a little freedom of expression and more coherancy with regards subject, content and flow of conversation.* (Paul)

Associated with this enhanced freedom of expression was a feeling that online it was easier to be oneself:

> *In cyberspace, you are protected against the misleading messages given out (without your knowledge) by your body, your face, your voice and your lifestyle. You can convey what you* want *to convey. You can be seen as yourself.* (Pat)

> *For example, I have become friends with a guy named **xxx** at work and we have daily in depth discussions by email on various topics - personal, current affairs, random points of interest. Yet the minute I'm face to face with him, its like all communication lines are down and I am so self conscious I am unable to raise a single opinion. (if I do, its likely to come across real harsh, in that 'knee-jerk' fashion I mentioned to you previously) I have just this minute asked him the question 'do I come across differently in email than I do face to face?' and his reply was 'In short, yes, but that is your nature.' Without the use of email, **xxx** would not have a clue about my nature - he, along with the vast majority of people that I have to interact with, would be basing assumptions about*

me on just a shadow of my character. I wish that I was able to be my real self all the time and not just in writing, it is very frustrating having my personality restricted in this way. (Nicola)

For many it was easier online to be more open with one's thoughts and feelings, and to discuss personal issues:

I tend to be much more open and less inhibited when using email especially when I can choose when to respond. (Andrew)

The main difference is that I talk a lot more about my feelings online, I rarely do that in the real world. Writing things down is a lot easier than talking about it. I even send my boyfriend emails sometimes. (Julie)

At work I email/chat with a woman on the other side of the office. We share problems and its good to get a woman's viewpoint. I guess she talks via email because of the confidential nature of the subject, When i meet this woman face to face I freeze up and mumble my words. I am not able to say face to face even 5% of what I say to her by email/chat….
The majority of the on-line communications are made because I am not able/happy to make them off line. Also if I was forced to make them off-line I would not say the right thing. Making them on-line makes me more open to my feelings and thoughts. I am able to word and structure the conversation much better. (Mike)

For some it was easier also to be more open about oneself, disclosing information which they would find difficult in a spoken communication situation, as David explains in this example:

*I can be completely myself when talking on line and don't find it necessary to hide anything apart from my one big secret which I would only ever dare tell someone if I knew them extremely well, knew I can trust them and could encrypt our communications. I can be much more open about **xxx** even in chats that are not specific to **xxx** and I have no qualms telling people about my Asperger's Syndrome. Instead of having to explain it to them I can simply give them the addresses of websites on the condition and concentrate on talking about me rather than my "illness".* (David)

Choice over self-presentation

Whilst there was a strong sense that for many it was easier to be oneself online, CMC also affords greater choice in how one portrays oneself, as these two extracts suggest:

> *Online communication, together with most written communication, gives me more time to consider what I'm saying; I therefore have the opportunity to be either far more honest or far more dishonest in the image of myself that I put across to others.* (Will)

> *Here the forums are run by Aspies and its part of the rules that we do not use our "real" identity on the Forum. We can all live in our own worlds - this is VERY important to an Aspie In the group conversations I will do some experimenting with how I present myself. I present myself as the person I think I really am. However I will not reveal too much of my true self. I still will only reveal this in a one to one ONLINE Communication.*
> *So yes I control myself and experiment but only in "public" on-line areas.* (Mike)

Adoption of a different role

Several of the interviewees felt that they assumed a role online which was different to that which they portrayed offline. There were various ways in which they felt they differed online, for example being more confident, supportive or sociable, or taking on a role as leader or organiser:

> *Perhaps I'm more confident (bordering on arrogant!) on-line than I would be off-line ... more forthright with my opinions, regardless of who I'm talking to ... more "risqué" with my humour ... So I have a much less significant role in society away from the computer.* (Ian)

> *I have been considering how quiet and ignorant I can be towards people when they are stood in the room with me and yet within minutes I can send them a perfectly upbeat and friendly email in response to something they may have said at the time.* (Nicola)

> *I find that when I am online, I tend to take on much more of a leadership/ organising role than I do whilst offline. For example, I organise* ***xxxxx*** *events a lot by email, but I'm less confident to take on such a role when on the 'phone, or face to face*. (Andrew)

It seemed as Mike suggests that for some the observer role is lost online, to be replaced by a feeling of inclusion:

> *In the ONLINE community I am a valued member and contribute freely . In OFFLINE I feel like an Observer, An outsider, an Alien. e.g. at work if there are a group of people talking I try and join in but fail. The conversation moves on, and/or my timing is not good and I get ignored.* (Mike)

For Sarah, the difference was that online she could lose some of her role as someone with Asperger syndrome:

> *I am less aggressive when I disagree, and appear to be rarely hurt or insulted. If I ever have lost control offline, for example, I do not express this. I lead a perfectly normal life, and leave much of my worries and Asperger's related occurances offline.*

Therapeutic benefit

As already discussed, for many interviewees there was the potential online to open up more about one's feelings and discuss personal issues with possible therapeutic benefits. The extra control over communicating when feeling upset gained from electronic communication can also enhance this. Additionally, online there was something to be gained from getting things off your chest as these two excerpts suggest:

> *It has been easier because the support forums are always there and you can access them 24 hours a day. Also having access to email has been easier because if I needed to talk to my friend about a problem I had, I could just email her and I would have got my difficulty off my chest. If I did not have email I would have to wait until my friend was in before I could talk to her.* (Claire)

> *its particularly good as you can work through your upset state as a constructive by product of producing the e-mail. You have to think when writing - choose words which have a certain life of their own, they need careful placing to say what you mean. To some extent the vocabulary you have will affect your thinking.* (Tessa)

Feeling protected and secure

There were many aspects of online communication which added to a feeling of safety. It was possible to be more guarded about how much one revealed of oneself online:

> *I believe that being guarded with your emotions online is positive (in particular, negative emotions which you realise you should possibly not harbour, for example, hurt if another person is unpleasant to you. The internet user is able to give the impression of feeling any way they wish to feel, and in real life, for those people who are less than capable of concealing how they feel (myself included), this would not be possible. The unpleasant person who has insulted you will then be discouraged from passing another insulting comment, if they believe it has not offended you.* (Sarah)

> *I certainly feel that I can control how much I reveal of myself online (or in letters). Face-to-face I can sometimes say too much as I'll trust anybody! A friend of mine says that she should "put her mind into gear before engaging her mouth", and I can identify with that! I can be focussing so hard on trying to understand what other people are saying that I don't think very much about what I am saying.* (Jane)

The distancing effect of online communication also seemed to create have a perceived protective effect, as the following quotes imply:

> *More, that i am able to just communicate without having to defend myself, very much at my own pace and wiothout having to be disturbed.* (Paul)

> *I fear phoning people and speaking directly to people. I find it easier to "hide" behind an email.*(Mike)

> *... I definitely like people to know I'm around when I'm on-line, even if it means incurring their wrath! Off-line, I'm more inclined to hold back and keep my feelings to myself, fearful of any negative reactions.*(Ian)

There were also suggested advantages to one's personal security through being unseen, such that misleading messages and confusions may be avoided:

> *Having AS means that I tend not to know people's true intention towards me so my mind can go crazy jumping to conclusions or missing the point trying to work people out. When all you have is conversation, it is unlikely that a guy will have ulterior motives as he has no idea what you*

look like. Maybe I'm just paranoid about the opposite sex, but I definitely feel that online chat provides me with a safer environment in which to talk freely (Nicola)

In a sense, what it provides protection against is being misread or misunderstood, which happens all the time in real life. In fact, I'm not even sure that 'real life' is the best word to use here: I should probably say something like 'meat space'. In cyberspace, you are protected against the misleading messages given out (without your knowledge) by your body, your face, your voice and your lifestyle. You can convey what you want *to convey. You can be seen as* yourself*.* (Pat)

It is also easier to ignore people online, as this interviewee explain:

It's also completely straightforward to avoid people who I find I don't like because I can simply block them from emailing me or messaging me, whereas in the real world it is much more difficult and not always possible to avoid contact with people I don't like. (David)

The anonymity of online groups was also seen as affording security, as well as enabling easier discussion of personal issues:

*I have never met the people I correspond with on **xxx**, and am not likely to. I think this makes it easier for me to tell them about problems that would be embarrassing if my 3D friends or colleagues knew bout them. The convention is to use screen names, and not to reveal exact names or locations, so anything I say should not be traceable back to my real person.* (Tom)

*I have set up a social group for people with **xxx**, and I find that most of the members prefer to be contacted by email as they do not have to give their full names, addresses or phone numbers. As a result they may feel much more secure and are able to discuss any issues they might be facing without being worried that they are making themselves more vulnerable.* (Jane)

Another feature of online groups which could contribute to feelings of protection was the availability of rules and moderation as David explains:

… everything said is recorded and I can notify AOL, MSN or Yahoo etc. if anyone breaks the rules, e.g. by being abusive and offensive or or pretending to be someone other than who they really are. (David)

In the above quote David is also highlighting the protective role of a permanent record online, something he mentions again in a different context. By looking back over conversations he could look for inconsistencies or discrepancies and then probe further, thus assisting him in judging character and authenticity, a skill which he felt related to having Asperger syndrome:

> *I have also found, and believe this to be one of the positive things about AS, that by asking the right questions I can catch people out if they are not being honest with me while not causing them any offence if they are genuine.* (David)

Others also suggested that a permanent record could protect oneself from misunderstandings or arguments:

> *A further problem with spoken communication is the a lack of a record, resulting in the possibility (if not probability) of your being misquoted, together with the likelihood of forgetting what you have been told and being too embarrassed to ask again (It's not always possible to take notes)…..*
>
> *Emails have all of the advantages of letters, they give me time to think about what I want to communicate; they allow me to dump my thoughts and then rearrange them; they allow me to check my spelling and grammar; they give me a records of any exchange and they are also reasonably immediate.* (Tom)

> *At work most communication with me is via email. Everybody then has a copy of what has been said and so this can avoid arguments!* (Jane)

As well as raising the ways in which online communication could afford some protection, several interviewees mentioned the risks they felt came from communicating with unseen or unknown people who may engage in undesirable behaviour:

> *As you don't see the people you talk to on the internet, you really don't know whetther they are telling the truth. You should never give your email address or your postal address to anyone in a chat room. People with Asperger Syndrome can be very nieve and gullible and easily led. They are literal so they believe what people say. They could get themselves into danger if they are not given guidelines as to how to use the chatrooms.* (Claire)

I do read discussion boards, for useful information and facts, but I think, probably through having Asperger syndrome, I much prefer one-to-one exchanges, rather as I am with you. Chat rooms can involve any number of people and I do not like the uncertainty of not knowing their personalities, or else the subject going in a direction I am unable to follow/understand.
I did join in a discussion group a few years ago and it ended up as a very negative and unpleasant experience; I am still traumatised. What I prefer is to identify those people I want or need to contact and then make personal contact, for what I think results in a much more positive experience. (Alison)

Anonymity is positive as people need not know who you are. It better enables freedom of expression. However, it is also negative, as people may do/say unsavoury things and there will be no real repercussions for that person. (Sarah)

Group participation

For many people taking part in a group situation was problematical, but online situations could eliminate some of the challenges faced by people with HFA/AS enabling group participation and a sense of involvement:

I think an Off Line community also has small EXCLUSIVE Sub groups. Which are impossible to break into. ONLINE you are all in the same area and your words are open to all. You are more open and honest. (Mike)

Also I don't get much chance to have a proper conversation with anyone these days since my Mum died. Also I am not very good at small talk or talking when I am involved in a big group. I also find it hard to talk when there are a lot of people talking together and I can't hear what people are saying. I cannot tune out the background noise. This is a sensory difficulty.
Online communication is very good for me as there is no noise and I can concentrate on what I am saying and what others are saying. (Claire)

… and enjoying the sense of belonging I have when I DO feel up-to-dateand in touch with my little global communities. (Ian)

However there were those who had found online groups which lacked a specific focus of interest to be inadequate to their needs:

*I joined a few general sites to meet people, to talk to them. One such hell hole is called **xxx**. I thought that it would be more honest. People having restrictions removed sayiong what they want. Ultimatlely it was very confusing. The competatvie edge on line is very healthy. For example it seemed like nobody would speak to you unless, A) you had a photo (the worse seemed to be better?) B) a natural ability to talk nonsense. So perception of people is high on the list in domains such as **xxx**…*
***….**And when i see what exactly these sorts of places are about, well, iget a bit shaky. You see, they are all about chatting. mmmmmm. I may sart to grumble.* (Paul)

Chat rooms have very little interest for me; they are too spontaneous and they seem to consist of people posting ill-considered nonsense together with stupid comments purporting to be humour. (Will)

Demarginalisation

The Internet had enabled many of the users to find a peer group, such that they could feel validated and less isolated. This may involve communication with others who have an ASD, but may relate to other personal concerns about which they felt marginalised, including mental health issues or issues of sexuality:

*Communicating with other people with ASD and reading they go through the same things I'm going through has made me feel better (*Julie*)*

The effect on my life is that I no longer feel as though I am the only one with my particular interests, and have made friends on the internet too. (Sarah)

I can openly talk about xxxx and how upset I am xxxxxx and everyone on these sites understands me and why I feel the way I do. In the real world very few people are able to relate to me on this matter. (David)

However one interviewee was concerned about the polarisation that could result from reducing the amount of contact one had with others whose views may differ and challenge one's own:

*When looking for a 'good' **xxx** forum trundled through loads and there was a definite masochistic streak in alot of them where people went over and over their bad experiences and then read other people bad experiences and it seemed like a down ward spiral. We all*

live in the world and a bit of mixing is a good idea painful though it can be. Not mixing and having your assumptions questioned means you don't have the opportunity to develop but instead is more likely to lead to stilted prejudices. Have the same suspicion about monks and nuns - can it really be healthy to disappear away - think you can only really deal with the world by interacting with it and dealing with everyday things and that does include people. That said everyday life can be very difficult for many people - in fact coping with that is a task in itself. (Tessa)

Gaining support

There are many factors already discussed which contribute to the supportive role online communication can have for the interviewees: being able to express oneself more easily and open up about feelings and personal issues; the enhanced control one felt over communicating when experiencing strong emotions; the feeling of security due to online anonymity; the potential to find others who have similar situations to one's own; and the therapeutic benefit of getting things off one's chest in text. The support which people obtained online may be from a forum, or from individuals:

*I use some of the '**xxx**' forums most days. These are principally mutual support groups for **xxx** and **xxx.** I can discuss issues that I would find it difficult to discuss face-to-face. I also enjoy giving support to people with more severe problems than my own. They are also fun communities (unlikely as it may sound).* (Tom)

As I mentioned before, I have a dear friend that I have a relationship with and it is both offline and online. I find that it is really helpful that I can communicate to her online as I don't get much chance to talk to her offline as she is so busy. Also, if I have a problem it is useful for me to be able to email her as I find it difficult to verbally express my feelings. I can write the down more easier. (Claire)

For some of the interviewees online support groups could be quite negative and distressing to participate in, as Paul comments:

*The other thing about some of the **xxx** sites is teh content……. It was full of the same words and sentances that i used to communicate my world. Ones like miserable, suicidle and self harming. At the time when i was investingating this world of email i didnt really feel up yo reading the heartache of others. I do try to be good spirited, and i felt that these*

folks ….. had no chances like me/ ultimatly i found it very upsetting and i felt angry that nothing was to be done. (Paul)

Benefits to offline interactions

For some of the interviewees, their experiences online had increased their confidence in some of their interactions offline as these excerpts indicate:

I think that sharing with Internet friends has made it easier for me to share personal concerns with 3D friends. (Tom)

It has probably made me more confident in my abilities to make friends, because I am able to do it online. Seeing how the people I speak to online handle exchanges and situations that would otherwise be difficult for me may have helped me somewhat in handling those exchanges and situations in real life. (Sarah)

it gives me a window onto other people's lives (maybe relevant that I have tenuous connexion/involvement with them?), and I can learn by observing the interactions beterrn them, and kind of watch the world go by with the comings and goings and changes in people;s lives. (Robert)

Integration in to the workplace

The established acceptability of electronic communication in the workplace seemed to be of great value to most of the interviewees in employment, a way in which their needs of a communication medium were inadvertently being addressed:

<you mentioned that you have to use e-mail a lot at work, and that this <is a good thing as you are comfortable with that method of <communication. I wonder how things would be for you at work if there <was no email?
So do I! I do use the telephone sometimes when I have to contact someone quickly or when someone calls me although the option is there for me not to do so as a "reasonable adjustment". The pressure of face to face or telephone communication tends to make me forget things so I find it is safer to use e-mail where possible as well as being less stressful. (Andrew)

I can not live without email - especially at work. I would not work in this office if there was no email (Mike)

Before I had email I used to communicate mostly by fax where possible. The difference over the last five or six years is that it's become so normal *to communicate in writing. My clients used to think I was kind of odd, sending faxes, but email is completely standard. People in the same office send each other emails! Can you imagine them sending each other faxes? (Usually there* is *only one fax machine for the whole office.) So I'm putting things in writing as much as I ever did, but it feels as if the rest of the world has caught up with me: my freakishness is less apparent.* (Pat)

Liberation and disinhibition

With the sense of liberation, however, there was a risk of losing control over one's interactions, which brings its own risks. One reluctant user of Internet communication stated strongly the neglect of real life which could result from communicating online:

It seems illogical that so many people sit staring at so many machines for so long as though they are being brainwashed by some alien intelligence. Often they seem oblivious to amazing natural sights around them. Stunting their true intellectual growth (Charles)

There was also a risk that face-to-face skills would be disadvantaged if neglected in favour of online communication:

Also, if a person uses the internet as their main source of communication, face-to-face interaction is not practiced and therefore would not improve. (Sarah)

Other issues related to the large amounts of time which could be spent online. An emergent problem for Ian, for example, was the struggle he had keeping up with all the online groups in which he had become involved. As his main hobby his online activity resulted in some rather large phone bills in the days before a flat-rate monthly charge. More recently he had found himself *"spreading his time quite thinly over quite a few different sites, and there never seems to be enough time in the day to achieve all I want to achieve on-line.."* He did refer to the possibility of his online activity being an addiction (and certainly referred to being "hooked" and needing a "daily fix") or *"possibly an Asperger's thing too"* such that he could feel some distress if he got behind on certain sites and had his routine disrupted.

Some other interviewees also made reference to large amounts of time spent online. Nicola implies some degree of addiction at times in her past:

> *Due to taking control of my own life recently I no longer feel the need or make time to go in chat rooms. I can however, clearly remember when I was in the depths of my chat room addiction - for me it was like attending a social event, especially when you go in on a regular basis and start to become familiar with other regulars. I distinctly remember a period of several weeks when I would come home from college, go online and chat constantly from 5pm til midnight.* (Nicola)

Mike also recognises the negative aspects of excessive amounts of time spent online:

> *Sometimes MSN will get me into a deep conversation which lasts till the early hours. NOT good as I get up at 4:30am.*

He also explains how associated with this loss of inhibition is the lack of acceptability to others of what would be perceived excessive or inappropriate use of Internet-based communication.

> *Some Normal friends with no AS understanding get very Annoyed with me using internet communication all the time. (including text) They are more natural with REAL communication, At work I have been Warned 3 times not to use email when I can use Face to face or telephone. I have since told them about AS and they have not warned me since.*

Disinhibition online can also bring potential personal vulnerability, which several interviewees mentioned and which was associated with the enhanced self-disclosure which could occur in this medium:

> *I tend to get carried away with some conversations, Get led into a false sense of security and may reveal more about my true self than I should have done. I get worried sometimes as I think that confidences will be betrayed.* (Mike)

> *So I'm very open and honest about myself with my trusted friends – perhaps more so than I ought to be really, although I'm not as naive and gullible now as I was when I first came on-line. Back then, I was far too public with many of my personal details and intimate thoughts, and I occasionally paid the price for that. Nothing serious or criminal, but still hurtful none-the-less.* (Ian)

> *I am rather wary of expressing my true self both online and off line. You have to be wise in who you are being honest with especially if you don't know the people that well. You can open up a can of worms if you are not careful.* (Claire)

This vulnerability is exacerbated by the permanent record involved in online communication, something which was conversely seen as being supportive to communication:

> *Having a record of what is being said can be a great advantage for me because it can take a long time to process information. However there can be occasions when what you write may be "taken the wrong way" and used as evidence against you. This actually happened to me in my last job - ultimately I won my case, but I went through hell for some time.* (Jane)

A unique form of communication

The insights of the participants have yielded key aspects of Internet-based communication in relation to their own needs, which can be summarised into three categories; online communication is a medium in which:

- **The unacceptable becomes acceptable**
- **The challenges of spoken communication are reduced**
- **There is access to extra facilities to support interaction**

Inevitably this sub theme overlaps with aspects of the others already discussed. However it draws together the aspects of online communication which match the characteristics of autistic communication.

The unacceptable becomes acceptable

In common with many other interviewees Andrew points out that *… the main advantage of email is that it takes away the need to respond in 'real time'* Being able to take one's time can ease the burden of communication in a way which does not seem possible in spoken communication situations. This is possible in synchronous forms of CMC as well as asynchronous forms:

> *In online communication it is generally regarded as ok to pause the conversation for a short while, giving me time to think about what to say next, and I can delete text that I have typed if I change my mind about wanting to say it.* (David)

Using MSN I can always type "back in 5" and pretend to make a tea but instead be working out what to say next. No one see's me or hears me. (Mike)

…and if you don't respond, or there's a delay, it can be passed off as bandwidth trouble. (Nicola)

As Tessa explains, with reference to email, it is possible to vary one's level of engagement with others online:

Thing about e-mail is that unless you leave it very long you're not likely to offend / alienate people by not replying immediately. It's only people you know very well ie family with whom you can drift about not communicating but being in their company without causing offense. Most people if you know them and are physically present expect you to be listening and interacting with them - ie there's a pressure on you to keep up. (Tessa)

The facility to take one's time online can also be beneficial to others who do not have an ASD, giving them extra time to reflect on information from someone with a different communicative style:

I often go into great detail about a situation that I am in and this can be a problem for people as they can only take in so much information.
With email this is not a problem. I email my friend and share with her situations that I am going through. She can cope with me going into great detail because she doen't have to read an email all at once. She reads it a bit at a time at her leisure. (Claire)

For some the real time nature of chat rooms (compared to email) was such that it was too fast and did not afford sufficient processing time. Being able to take one's time did not seem to be so acceptable or feasible here:

On chat rooms, we are expected to give instant results and responses. Whereas e-mails take a more leisurly pace. Or even at ones own personal speed. This time is essential for me. I need time to see what the question is and how it relates to me. (Paul)

It is worth mentioneing tho, that chatrooms hoild some parallelism to live social situations, insomuch that it occurs in real time, requiring one to think on tyhe spot, cf message boards. (However, I prefer to use MSN, as I can easily make up excuses for slow replites &c, and I would never be bothered to log into) (Robert)

Whilst there is the possibility to take more time when engaged in asynchronous CMC, there are drawbacks due to the lack of interactivity:

> *Although email works for me in enabling me to express my feelings, it can be a disadvantage as sometimes I need an immediate response.* (Claire)

> *Talking to someone on the phone can also mean you get simple things sorted out a lot quicker, it seems there's a lot more potential for dithering around and not actually getting things decided on the internet.* (Craig)

> *'Live' Internet communication feels more interactive, for sure. It's much more of a two-way conversation than non-live methods. It was live communication that fascinated me the most in my early days on-line, as it felt so liberating to feel freely able to chat with anyone in the world without feeling uncomfortable (which I would do in a face-to-face situation or on the phone).*(Ian)

It is also possible online to "lurk" and take a less involved role in a group situation, something which could be seen negatively in a face-to-face situation, but which had its benefits for some of the interviewees, enabling involvement at a level suitable to their needs:

> *About Lurking, Well one of the things I would wait for is that What I want to say fits well into the conversation.* (Mike)

> *the aspie e-mail group previously mentioned fore felt like a community and unlike a live one you could 'lurk' undisturbed without making others unintentionally uncomfortable. Live groups tend to expect regular contribution which is stressful as you're supposed to be alert the whole time - I tend to drift off and that is of course what people sense and then pounce on me with a question to bring you back into the fold.* (Tessa)

> *Being able to lurk before engaging more actively. Definitely an advantage, as I often fee la bit left out in a live sitatuaion* (Robert)

Lurking may also support the process of finding suitable people with whom to interact as Sarah explains:

> *Lurking is an excellent idea, since it gives new members and idea of the general ethos of the group, they can see whether or not they wish to join the site. Some people do not, for example, enjoy interaction with*

sarcastic people, and if the people are sarcastic, they know not to join the site. If the people on the site appear friendly and welcoming to new people, they should consider joining. (Sarah)

The "norms" of conversational structure, used in spoken interactions by most people without conscious thought, differ online, with tolerance of, perhaps, a broader range of behaviour. There is less expectation of small talk online as Will says with reference to email:

It's fairly impersonal and therefore lends itself to the exchange of actual information rather than social chitchat. (Will)

This may vary with the form of online communication as Paul explains with reference to chat rooms:

Communicating i can do but chatting can leave me cold and lost. So i dont really have much time for chat rooms. (Paul)

Although people may be more likely to come to the point online, email can perhaps accommodate those who need to go into detail in their communication, as Jane explains with reference to other people on the autistic spectrum:

With a couple of my friends with AS, however, there is a problem because they talk endlessly about their special interest. It can be difficult to turn the conversation round to what you want to talk about. With email you can just ignore the pages of information on ***xxx*** *etc.* (Jane)

The challenges of spoken communication are reduced

As will be evident from the descriptions of themes so far, the stress of communication can be alleviated online where the processes involved may be simplified with the elimination of nonverbal and turn taking aspects of communication:

Meeting them online is more comfortable for me than meeting people in real life, as I hardly have to worry about non-verbal communication (Julie)

In a online conversation its harder to But in. Meaning that when you type a a message (on msn) it may naturally appear before or after someone else and therefore no one accuses any one of butting in. A longer message takes longer to type and appears later than a quick reply. (Mike)

There were also references to the ways in which the absence of another person could ease the process of communication, as has already been discussed; visible signs of nonverbal and emotional responses are hidden, self-disclosure may be enhanced due to anonymity, and one may feel less self-conscious or stressed due to the lack of presence of another:

> *Also it is impossible for someone to 'put you on the spot' in webchat because there's no-one stood there watching for your reaction* (Nicola)

> *Online I have only the words to look at and don't have to worry about what the other person looks like or is doing with his/her face or hands etc, and, of course, eye contact is not necessary.*
> *Overall, and in conclusion, for me the advantage of online communication isthat essentially I only have to deal with words, rather than with a real flesh-and-blood person* (Jane)

> *On-line gives me time to think about my answer. People can not see me when I am trying to answer. I feel less intimidated.*(Mike)

The enhanced control which may be experienced online, due to a reduction in sensory overload has already been described. However although environmental distractions may be reduced in some cases others may be added for example flickering screens or the visually busy nature of some website interfaces:

> *I find the flickering of the screen very hard to cope with, and avoid reading documents of any length on-screen.* (Simon)

> *Firstly the interface presents some problems. some chat rooms can have flashing stuff going off, or scrolling bars. These detract from the main body of a chat room for me. So i end up quickly daydreaming. So i can end up missing so much.* (Paul)

Also if accessing the Internet in public locations there is less control over interfering stimuli which can be a cause of frustration as illustrated by these two quotes:

> *Although the format of the internet i find accesable and usuable. there is still the real time problem when using the internet. For instance people making excessive noise when at computer stations. People talking across comptuter stations, people generally being people.* (Paul)

There is something I need to tell you - I am trying to work in an extremely noisy public library. There is a loud discussion group going on in the middle and I just can't believe it is being allowed!
As a result of the noise (sensory overload?) I am completely unable to concentrate on answering your questions and I think I need to leave.
Sorry - I shall return this afternoon. (Alison)

There is access to extra facilities to support interaction

From analysis of the interview data it became apparent that there are facilities online which may assist communication for people with HFA/AS. These combine certain features of other forms of written communication with the capacity of the Web as a global network which can store and transfer large amounts of information at relative speed.

Several interviewees highlighted the value of being able to proofread and edit their communication:

> *Secondly, anything you are about to say can be read through and edited before you hit 'send' which is a great mechanism for controlling those random outbursts that would in hindsight make you feel embarrassed.* (Nicola)

> *I can change anything I don't like the look of, or that I think would look/sound better worded differently, before its intended recipient sees anything. Being able to proof-read beforehand is such a blessing for me. While I'm on-line, these things alone relax me, and make me less self-conscious. They just don't exist when I'm talking face-to-face or on the phone to someone.* (Mike)

The permanent nature of online communication could also be an asset, allowing more processing time:

> *I do like communicating with people on line as i have time to digest what is being said. If i needed more time i could print it off and go read it at home and then respond.* (Paul)

> *By having the messages written down I can re-read them and can allow for as much mental processing time as I need. I have time to think, and I also have written record of what has been said.* (Jane)

With respect to online groups the permanent record available within archives can assist the process of integrating into a group and adapting to social or communicative norms:

Archives of group interaction are clearly advantageous to a person with AS, since they can analyse, if they so desire, the comments passed by the interacting parties, and discover model responses and ways of responding to different comments. Archives also serve as evidence against which an AS patient may measure their improvement with regard to interaction. (Sarah)

However as mentioned earlier, a permanent record can also create feelings of vulnerability, with one's thoughts committed to text, and potentially open to misinterpretation, misuse or abuse.

The benefits of the Internet in terms of information storage and retrieval were highlighted in the context of supporting the process of "shopping around" for new friendships as well as assisting in the disclosure of having AS/HFA, as David explains in these two excerpts:

I would say that making friends on line is a lot easier than in the real world. Making friends in the real world takes time as I need to get to know them and they need to get to know me. Making friends on line is easier in this regard because I can read their profile and they can read mine so we already know quite a bit about each other before we even start chatting. Furthermore I can seek out like minded people by doing keyword searches on the profiles in the members directories, which is almost impossible in the real world…

Secondly it is a lot easier for me to tell people that I have Asperger's Syndrome. I can usually find an appropriate point during the conversation to tell them about it. But what's most significant is that instead of me having to explain it to them as I would during a face to face chat I can simply direct them to a website on the condition which explains it much better than I ever could. I would consider it much more appropriate to tell someone I'm chatting to on line where they can find out about the condition whereas the nearest equivalent for a face to face conversation would be to give them a leaflet on the condition which is not usually appropriate with someone I've met in a pub, at a party or at a friend's house etc. (David)

The existence of explicit rules to guide interaction in online forums can assist those for whom the intuitively acquired rules offline may remain elusive as this quote from Nicola implies:

In real life you are expected to know how to behave socially once you reach the age of about 12 so after that people would think you were odd

or being funny if asking for guidance! As people are new to online chat all the time there is no stigma about getting things wrong and folks are always happy to explain it to you. (Nicola)

The availability of moderation in some groups could facilitate the implementation of such rules, and also afford protection to members, something which David values:

…in light of certain negative experiences I now tend to avoid unmoderated groups. First people often post nasty offensive messages and second unmoderated groups often end up dominated by spam. ***XXX*** *is a good moderator and he promptly deletes any material that violates the rules and if necessary revokes the author's membership of the group.* (David)

Tessa however warns of the risks of over-moderation in online forums:

Did register with a ***xxxx*** *forum but despite it being very interesing it was overmoderated to the point where someone was removed for disagreeing with the moderator on a topic - she had a very interesting point of view which challenged the moderator. Thought a moderator was suppost to ensure fair play as a chairperson so pulled out.* (Tessa)

Summary

The words of the participants in this study have provided valuable perspectives on the role and relevance of CMC for people with ASD. By acting as observers of communication, and relating their experiences and opinions of CMC, the interviewees have identified aspects of online communication which match characteristics of autistic communication, with implications for control, clarity, nonverbal communication and social interaction. Their insights illustrate how CMC may be liberating, which may be empowering or disinhibiting and problematic for autistic users. In the next chapter I shall examine these findings in relation to current theories and research in the fields of autism and computer-mediated communication.

CHAPTER 8: OVERALL DISCUSSION

The purpose of this study was to explore how people with HFA or AS experience the Internet as a communication medium. In this chapter I shall discuss the themes which emerged from the interview data in the context of the survey findings and also previous research and theoretical accounts. In particular I shall explore how the interviewees' experiences, motivations and perceptions may be viewed from a uses and gratifications perspective which posits that people use particular communication channels to satisfy their individual needs and motives. Within this framework, the analysis provides not only a model of the relationship between computer-mediated and autistic communication, but a wider view of the potential of CMC to fulfil *individual* needs and motivations. The discussion will begin with an examination of the observational and analytical approach which was evident from analysis of the data. I shall then explore how, as a group of people with AS or HFA, the participants' contributions have elucidated their strengths and needs regarding communication and social interaction, and go on to discuss how CMC may break down some of the social and communication barriers which contribute to their disability, enabling them to address their own particular needs as other Internet users do. The chapter also includes reflections on the methodology in terms of limitations as well as the experience of interacting online with this group of people in the course of collecting data. I shall also consider the implications of these research findings in relation to future research directions and also their practical significance for people with HFA or AS, their families and carers, as well as relevant professionals and service providers.

Communication analysts

In their scholarly guide to CMC, Thurlow et al (2004, p81) argue that "we can learn more about the nature of human communication when we look to see how it is affected by technology." In this study, this seems to be reflected by the way in which many of the participants discussed issues pertaining to communication in the course of the interviews, as well as the resultant themes of analysis. Like the shy interviewees in Scott's (2004) research, the participants in the current study "proved themselves to be superb lay anthropologists." Despite their deficits of social communication, interviewees

showed astute awareness of these difficulties in relation to the communicative behaviours of neurotypicals, as well as insight into Internet-based communication. Characteristic perhaps of having superior systemising skills (Baron-Cohen, 2002a), participants were often analytical in their approach to answering questions, and there was resonance with Williams' (2004) analysis of the autobiographical accounts of ten individuals diagnosed with AS or HFA, which yielded a theme of "distance between self and other people" and sub-themes of feeling like "a detached scientist", "an alien" or "an onlooker." Analysis of first hand accounts of experiences of autism from five personal web pages also highlighted themes of "a sense of alienation" (Jones et al., 2001) and "awareness of communication/comprehension difficulties" (Jones & Meldal, 2001).

Communication needs

There were four aspects of communication which were identified as problematical: clarity; control of a complex and interactive process; nonverbal communication; and the role communication plays in maintaining social contacts.

Also very evident was the feeling that communication is a very complex process, involving the integration of information from a number of different sources and the simultaneous execution of a number of cognitive tasks which people without autism achieve without undue thought. For the research participants however this was not such an intuitive process. To reiterate the words of one interviewee who summed this up with a vivid analogy:

> *Communicating is like your first driving lesson; so many things to do and it all feels so unnatural and like you'll never manage to do all of these things together.*

The struggles to control the complex and multifaceted process of interpersonal communication, which the interviewees described, are perhaps manifestations of impaired executive functioning (Frith, 2003). The need to exert more control over communication with other people seemed to be a major motivation for the use of the Internet as a communication medium.

One feature that came out bvery clearly from the transcripts was the difficulties of emotional control participants experienced during face-to-face communication. These difficulties were seen as highly disruptive to interpersonal communication. While several cognitive theories of autism have

implications for emotional awareness (in particular a model based on an impaired theory of mind) and self-regulatory processes (due to impaired executive functioning), emotional dysregulation is not a core diagnostic feature of autism. It would seem that this feature is under-emphasised in the psychological models of this condition as it is clearly expressed as a barrier to interpersonal relations in the data collected here. Perhaps more focus on qualitative methods of analyses could promote a better understanding of the everyday effects of the psychological impairments associated with Asperger's syndrome.

Nonverbal communication was identified as a particularly challenging aspect of social interaction. The use of communication media in which this feature was diminished was seen as one way to ease the struggle of social interactions. Experimental investigations imply that increasing the degree of multimodal information (linguistic, prosodic, visual nonverbal) does not help and may even hinder the recognition of complex mental states in people with ASDs compared to matched controls (Golan et al., in press; Pierce et al., 1997). Regional cerebral blood flow studies suggest that cross-modal emotional stimuli place not only greater demands on the attention capacity of people with HFA compared to those without the condition, but are also processed as competing rather than complementary sensory experiences (Hall et al., 2003). In parallel with the conclusions from these studies, as well as a weak central coherence account of autism (Frith, 2003), analysis of data from the current study implies that participants perceive themselves as having difficulty integrating nonverbal cues and other sensory stimuli in the course of social interaction.

There did not appear, however, to be a straightforward relationship between absence of nonverbal social cues and people's communication preferences, as had been indicated by the survey results. Telephone communication was seen as particularly difficult, more so than face-to-face communication. Interviewees' comments indicated that many of them felt there was some benefit to be gained from visual nonverbal communication, in terms of turn taking and emotional states, albeit to a lesser degree than people without autism. In common with some of the personal accounts analysed by Williams (2004), some participants had learnt skills in an attempt to compensate for their difficulties with nonverbal communication, whilst others felt their ability was more intuitive. Reviewing experimental studies of emotion recognition carried out with high-functioning autistic individuals, Golan et al (2006) suggest that "recognition of basic emotions might be relatively preserved (or compensated

for) in individuals with ASC, but that they show difficulties recognising more complex emotional states." This may account for the perception of interviewees who felt that at a *basic* level, they did gain some emotional information from visual cues, and hence did not like telephone communication in which this supporting information was lost. However recent experimental research carried out by Back et al (2007) indicates that individuals with autism use visual information from the face in order to recognise *complex* mental states. Although autistic subjects were generally poorer than controls at inferring complex mental states from dynamic or static video images of whole faces, there was no specific deficiency in their ability to recognise emotions from the eyes, regardless of whether these were in or out of context. Findings also indicated that for both controls and autistic subjects there was a greater reliance on information from the mouth region than the eyes when attributing mental states. The authors suggest that executive dysfunction or impaired communication might account for the social impairment of autism rather than isolated deficits interpreting mental states from visual information. It seems the role and relevance of nonverbal communication in the social interactions of autistic people is complex and requires clarification. However it was an important factor to the interviewees in their assessment of different communication media in relation to their own needs.

From the analysis it seemed that the interviewees had struggled to clarify the interaction between their communicative abilities and their relationships with other people. In line with the findings of studies by Muller et al (2008) and Jones and Meldal (2001), some desired relationships but were hindered by their struggles with face-to-face communication. Others were less concerned about social interaction per se, but needed ways of keeping in contact with others on their own terms, with minimal pressure on their communicative difficulties. This may be achieved through shared interests and structured activities, or by the use of CMC.

Having discussed the communication challenges faced by the participants, I shall now examine how they use CMC to fulfil the need for a more controlled and less stressful communication situation, one in which they could relate to other people at a level they feel comfortable with. Where appropriate the discussion will draw upon previous research and theory to contextualise the findings of this particular investigation.

The unique nature of online communication

As discussed in the last chapter, the overall analysis of the Internet as a communication medium was that it was one in which: the unacceptable became acceptable; the challenges of spoken communication could be reduced and there was access to extra facilities to support interaction. There were various aspects of online communication which contributed to this perception, the most prominent being its narrow bandwidth, permanence, and flexibility in terms of pace of interaction.

The implications of CMC for people with ASD may not be accounted for by deficit models of CMC (as discussed in Chapter 3) which predict that loss of visual cues online would compromise interpersonal dynamics, nor by compensatory approaches which posit that people engage in strategic cognitive deliberation and communicative behaviour to compensate for media limitations. As indicated by the interview data, for people with ASD the perception is that the restricted bandwidth of CMC may actually benefit interpersonal communication by simplifying the processes involved and lessening the burden on their impaired cognitive capabilities and the potential for sensory overload, particularly in group situations. Rather than having to compensate for limited social cues online, people with ASD may actually be able to use CMC to compensate for the limitations they face offline.

Similar to the participants in studies by Egan et al (2006) and Todis et al (2005) who had acquired cognitive impairments, the interviewees in this study reported feeling under less pressure online, with more time to process and construct messages, and therefore bypass the disabling effects of autism. There was a strong sense of control over communication which could be gained online compared to face-to-face situations: control over one's emotional responses as well as the reactions of other people; control over the structure of conversations in terms of pace, topic and turn taking.

There is a suggestion from the survey and interview data that the benefits of reduced bandwidth of a communication medium, with the loss of visual cues, may be compromised by synchronicity or auditory aspects of communication. Although some interviewees were using chat rooms others did not like the real time element of these forms of CMC. According to the survey, live online chat was a less popular way of communicating with other people compared to email, face-to-face communication, conventional mail and texting. Telephone was the least popular form of communication. As discussed before, this was attributed

to the loss of nonverbal cues by some of the participants. The real time element was also seen as a barrier for some interviewees. Participants mentioned the permanence of text, which permitted extra processing time, as an advantage of online communication. The use of synchronous speech, rather than text, in the absence of visual nonverbal cues may account for telephone being less popular than the other forms of communication, including live online chat.

When considering the relatively low preference for live online chat, it should be reiterated that data were collected at a time when instant messaging was still less widely used. As well as the pressure to respond in real time, critics of chat rooms also cited lack of focus or interesting content, as well as the unknown identity of others online, as reasons for their lack of interest. These issues are less pertinent when engaged in the more personal form of communication characteristic of instant messaging. Interviewees who were happier with synchronised CMC all mentioned their use of instant messaging as well as chat rooms. There was also evidence that there were ways of lessening the stress of a faster pace of communication, which resonate with Leary's self-presentational theory of social anxiety (Leary, 1986). This theory states that self-presentational anxiety is reduced in situations where there is a possibility of external interference with communication as any social interaction difficulties may be attributed to the external factor. As Roberts et al (2001) point out online "the absence of non-verbal cues, the time taken to type messages and the variable response time in sending and receiving messages are all likely to be interfering factors in the communication process." Interviewees mentioned that it was more acceptable to pause online and that they could make up excuses relating to bandwidth limitations or the interference of other priorities (for example going off to make a cup of tea) as a way of buying time.

From the discussion so far it appears that people with AS or HFA may use CMC to bypass some of the cognitive and perceptual difficulties which affect face-to-face communication. This seems to be due to enhanced control as a result of a different pace and a reduction in nonverbal communication. Additionally there were other ways in which Internet-based communication may alleviate the social disability of autism, ways which are also evident in empirical studies and theories pertaining to the use of CMC by other groups, as I shall now discuss.

There are parallels with the findings of studies of CMC and shyness, which indicate that shy people report feeling better able to express themselves and more confident online (Roberts et al., 2001; Stritzke et al., 2004; Yuen & Lavin, 2004). In accordance with a self-presentational theory of shyness, this

phenomenon has been attributed to the lack of nonverbal feedback online, as well as anonymity and greater control over message construction to the benefit of how one is perceived by others. These perceptions were certainly evident in the participants' responses; however there are additional benefits for people with ASD due to the reduced number of communication and contextual cues which creates a more conducive forum for self-expression.

As discussed in Chapter 3, the lack of visual cues, potential anonymity and time to reflect, construct and edit messages online have implications for interpersonal dynamics with the possibility of enhancing relationships with other people in some instances. These features may promote hyperpersonal interaction (Walther, 1996), enhance self-disclosure (Suler, 2004) , and remove "gating features" which deter the formation of face-to-face relationships (McKenna et al., 2002), effects which were all reflected in the themes of this analysis. Participants reported benefits to their self-expression and self-presentation, as well as the security that came from being judged on their words and not the impressions they may give out in a face-to-face situation. Similar insights emerged from research into CMC and shyness (Roberts et al., 2001) and also disability (Bowker & Tuffin, 2002; 2007; Todis et al., 2005), implying that online people had "the opportunity to enjoy a more socially valued subjectivity and a more positive identity" (Bowker & Tuffin, 2007). By avoiding the superficial, negative, or prejudiced perceptions of others, the potential for comfortable social interaction is improved. Additionally, participants in this study indicated that the Internet helped them to find similar or like-minded others, people with whom there was a common interest. Similar to the suggestions of Amichai-Hamburger and Furnham (2007) regarding the potential benefits of the Internet for socially inhibited individuals, this was seen as a way of improving the prospects of cultivating positive relationships with other people. The SIDE model of CMC (see Chapter 3) may also be relevant to this perception. According to this theory, in the absence of nonverbal cues online participants form feelings of connection to others based on *perceptions* of social category, shared interest or similarity.

In addition to the possibility of finding similar others, bypassing potentially negative first impressions and benefiting from enhanced intimacy online, the social impairment of autism may also be alleviated by being better able to manage the complex process of communication when interacting via the Internet. Thus people may achieve better control and more choice over the intensity of their relationships with others, thereby attaining a level of

involvement which fulfils their own particular needs and, for some, resolves the conflict between the need for individual self-expression and the desire to belong to a large significant group (Amichai-Hamburger & Furnham, 2007). There are parallels between this study and Markham's ethnographic account of virtual communities in which the theme of control emerged as a key issue for participants, particularly in relation to self-presentation and self-expression, but also the extent and nature of one's involvement with others (Markham, 1998). In addition to being a less intense, more permanent form of communication with flexibility of timing, other advantages of CMC which emerged as significant for the social interactions of participants in this study pertained to online groups. Online it is easier to vary one's level of engagement, perhaps to "lurk," in a way which would be unacceptable in spoken communication situations. Once again this affords participants more choice over their level of involvement, as well as time to evaluate and adjust to the dynamics of the interaction. Additionally, the availability of explicit rules to guide interaction and moderation to ensure adherence to group norms were seen as ways in which group participation could be eased for people with ASD, who struggle to discern the tacit rules of social interaction.

Similar to writers who warned of the inferior nature of online relationships (for example Cummings et al., 2002) and the risk that CMC may exacerbate the problems of less socially confident individuals (Erwin et al., 2004), the limitations of online social communication and relationships were highlighted by several participants in this study, for whom online interactions were not seen as adequate substitutes for offline relationships and opportunities to use and practice face-to-face communication skills. However for others the Internet had been instrumental in decreasing loneliness and expanding social networks, as well as gaining support from others either in the context of a supportive group or on a one-to-one basis.

The participants' perceptions of CMC can be interpreted as fulfilling the conditions stipulated by an appraisal theory of comforting communication (Caplan & Turner, 2007) which were outlined in Chapter 3 (see "Theories of computer-mediated social support"). As already discussed, the participants felt better able to express themselves and open up about personal matters, due to the greater control they felt over communication when online compared to offline situations, as well as the anonymity of CMC. They are also more able to shop around for people with whom they find personal discussions more comfortable, people who have had similar experiences or in similar situations,

who are interested in supporting and sharing with others. The relatively uncomplicated nature of CMC also serves to diminish the effects of sensory over-stimulation and emotional dysregulation for people with AS or HFA, thereby easing the cognitive challenges involved in focussing on personal thoughts and feelings. Finally CMC may facilitate the therapeutic effect of self-narratives as one participant articulated:

> *its particularly good as you can work through your upset state as a constructive by product of producing the e-mail. You have to think when writing - choose words which have a certain life of their own, they need careful placing to say what you mean. To some extent the vocabulary you have will affect your thinking.*

As Roulstone (1998) points out, new technologies such as the Internet can bring serendipitous benefits for people with disabilities, a point implied by the comments of one of the participants in this study with respect to the workplace. This study has highlighted the ways in which CMC may be liberating for people with AS or HFA, enabling them to interact with others on a more equal and comfortable basis and to exercise greater choice and control regarding self-presentation and self-expression, with implications for interpersonal relationships and social support. This could be empowering but the participants indicated that with the sense of liberation there was, conversely, the risk of losing control over one's interactions, similar to the online disinhibition effect described by Joinson (1998), Collins (1992) and Suler (2004).

Participants were aware that their enhanced self-disclosure when online could bring potential personal vulnerability, particularly when communicating with unseen or unknown people who may engage in undesirable behaviour. Their comments regarding this type of risk prompt speculation that perhaps the element of invisibility of CMC may serve to alert participants to the risk of deception by others, something which they would perhaps be less aware of in a face-to-face situation. They may also be afforded more time, and a less complex communication situation to weigh up the online behaviour of others, as well as a permanent record of communication to assist them in doing this.

In her review of treatment approaches for autism Howlin (1998) raised the risk of obsessive over-reliance on computer interaction and withdrawal from real world interaction for this group. Although these individuals were at a higher functioning end of the autistic spectrum than the main focus of Howlin's review, there was evidence of some behaviours and cognitions symptomatic of problematic Internet use (Caplan, 2002) by some of the participants: excessive

amounts of time spent online; negative personal, social or occupational outcomes (for example financial problems or negative reactions from family, friends or employers due to excessive use); and the perception of greater social control when interacting online with other people. According to Caplan's cognitive theory of problematic Internet use and well-being, people who have difficulties with social interaction, see themselves negatively in terms of their interpersonal skills and are more likely to develop a preference for CMC, perceiving it to be less threatening and more satisfactory than face-to-face interactions, indeed quite possibly liberating (Caplan, 2003). Operant conditioning may lead to increased use of CMC and distorted perceptions differentiating online and offline interactions, with the possibility of excessive and problematic Internet use (PIU). There is an implication therefore that people with AS or HFA are at risk of PIU. However it is worth here reiterating the view of Davis (2001) and recommending that the suitability of the Internet as a communication medium for people with AS or HFA requires individual evaluation of its potential to empower as well as the risk of dependency.

To sum up the discussion so far, this study has identified the ways in which a group of people at the high-functioning end of the autistic spectrum use computer-mediated communication to fulfill their communication needs as described by the uses and gratifications approach to computer-mediated communication (see Caplan et al, 2007). The study has also highlighted more broadly their perceptions of communicating in face-to-face and other mediated situations, indicating factors which may influence the perceived utility of a particular communication mode. In common with research findings and theories pertaining to CMC, the visual anonymity, permanence and different timing of Internet-based communication have implications for self-expression and self-presentation, with the potential to affect social contact and networks, resources for social support, and integration into the workplace. More specifically for people with HFA or AS, perhaps, the flexible timing and reduced bandwidth of CMC generate a less complex situation and hence more control over their interactions with other people with the potential to compensate for their difficulties with spoken communication. It should be emphasised however that as Markham (1998) noted regarding her account of online communities, "Internet users do not comprise a single culture, but enact innumerable cultural forms." As was the case in her study, the participants in this project varied in their reasons for using CMC, and their level of attachment and commitment to online communication. Markham interpreted the ways in which online participants framed CMC as falling along a continuum of *tool* to *place* to *way of*

being. Similarly participants in this study spoke of the ways in which the Internet was a tool which facilitated information transfer, self-expression, and interpersonal interactions, more easily than in face-to-face situations. For others there was also an element of the Internet being a place for interaction with other people, in the context of a group or a community. The liberating effects experienced online in terms of self-expression and easier interactions with others, were such that for some it seemed easier to be oneself, perhaps akin to the *way of being* end of Markham's continuum.

Having discussed the research findings in relation to relevant research and theory I shall now explore how they are contextualised by the methodology used in terms of limiting their interpretation and the insight provided for me as a researcher experiencing online communication with individuals who have AS or HFA.

Discussion of methodology

For me the most powerful aspect of conducting this research was the great insights shown by participants in the course of being interviewed, which were often articulated with eloquence, and also showed warmth and humour. Similar to the experiences of Scott (2004) in her interviews with shy people, and also Egan et al (2006) with survivors of traumatic head injury, the participants seemed to move away from their autistic identity producing responses which challenged stereotypes. My experience was certainly not dominated by perceptions of oddity or aloofness on the part of the interviewees. Dependent on the length and depth of their emails, as well as the pace of email exchanges, I warmed to the people interviewed and found the experience enjoyable and engaging. There were also various aspects of this form of interviewing which I found to be beneficial to the process of data collection and analysis as I shall now discuss.

I valued the longitudinal aspect of the email interview, and the time to reflect and plan for each exchange, which seemed to contribute to the richness of the data obtained. These aspects also enabled me to consider and adapt to the particular online interaction style of individual participants, which very likely made for a more comfortable interview situation for me as the researcher, reducing anxiety about misunderstandings and sensitive topics, with the potential to cause offence or upset. It was also reassuring, and indeed beneficial, to have a permanent record of the dialogue as it developed, assisting further the ongoing reflection conducive to the interview process, but also

enabling me to follow up points at a later stage, something which is less possible in the person-to-person situation.

Also of value was the enhanced interplay between data collection and analysis which was facilitated by the ongoing nature of email interviewing, such that new topics could be incorporated into ongoing interviews in the light of emergent analyses of data collected from the participant himself, or from other interviewees.

Interviewing people online about their experiences of online communication was beneficial in that it encouraged reflection on the research topic for me and also the participants. Additionally it afforded me some limited experience of the sort of interaction which was the subject of discussion, which added to the depth of data collected.

The risk of the prolonged, rich dialogue and rapport which was possible online during these interviews was the potential for the researcher-participant relationship to become too involved. Hence the drive for online rapport was constantly negotiated in the context of the risk of an unduly intimate relationship developing and the need for appropriate boundaries. This was achieved by carefully considering the social use of language, and establishing a clearly defined ending to the interview.

For the purposes of this research, given the richness of the data obtained, email appears to have been a technology which enabled this group of people with HFA or AS to provide their own detailed perspectives on the research topic, which suggests it may have wider utility. Various writers have identified the need for people with autism to contribute more actively to discussions or research which pertain to them (Aylott, 2003; Hurlbutt & Chalmers, 2002; Muller et al., 2008), in order to counterbalance the limitations of professional viewpoints (Smukler, 2005). This piece of research is a demonstration of how the use of the Internet-based communication may address this need.

However it should be noted that as a researcher with a background in speech and language therapy who therefore has experience and awareness of communication disorders, generalisability of my perceptions of the online interactions of high functioning autistic people cannot be assumed. The perceptions of a different person in a different context could contrast markedly from those described here. Similarly consideration must be given to my influence over the interviews due to my clinical background and interest as a researcher. The research findings should be interpreted within this context.

Additionally, although a purposive approach to sampling was taken, the perspectives of this small group of research participants cannot be assumed to be representative of all people with HFA or AS. As was the case with the survey, the sample was biased toward Internet users, who typically have higher incomes and are more highly educated. However by taking into consideration relevant emerging concepts and aiming for diversity when constructing the sample, the researcher endeavoured to limit error and maximise the validity of findings (Murphy et al., 1998, see Chapter 3 of this thesis "Generalisability and validity"). Also data were subjected to rigorous and systematic examination, and the credibility of results has been evaluated in the context of the survey findings, as well as relevant theory and research as discussed in this chapter. Nevertheless, it must be stated that analysis of interviews with a different group of participants may have differed to the one reported from this study, in which negative perceptions and experiences of CMC were less evident than endorsements of its utility. Informal comments from the parent of a potential survey respondent, as well as the professional coordinator of a social support group for people with AS or HFA, were less positive in their outlook on the safety and appropriateness of CMC for this group of individuals (see also Barnhill, 2007 for anecdotal reports from the parent of an adult son with AS). The final comment to make regarding the limitations of this piece of research, does not however pertain to a methodological limitation as such, but rather the rapid rate of technological progress since the commencement of the project. There is now more widespread use of facilities such as web cams, instant messaging, multimedia applications and social networking sites. Therefore, inevitably, the findings cannot fully account for the use of CMC by people with HFA or AS, consistent with the situation at the time of writing.

Future research

Although theories of CMC can explain some of the findings of this study, there is a need to look further afield and to consider other models to take research into this area forward in the future. Given the indication from this study that the Internet may be a means by which self-empowerment could be achieved for people who face difficulties with social interaction, examination of the empowerment literature provides potential frameworks on which future work could be based, and which encompass some of the themes revealed by the current study, for example gaining support, control, self-expression, group participation and integration into the workplace. Feste and Anderson (1995), for example, based an empowerment education programme around the

implications for well-being, self-image, motivation, adaptability, stress management, problem-solving, social support, self-awareness and hope.

Dempsey and Foreman (1997) view the key components of empowerment as self-efficacy, sense of control, participation and collaboration, meeting personal needs, understanding of the environment, personal action and expression, and access to resources. In their practical guide to empowerment for people with learning or mental health support needs, Dowson et al (1998) define empowerment in terms of "being enabled to have increased control over one's own life" (p5) and propose it as encompassing the following: having information, being listened to, getting a response based on what has been said, and appropriate division of power.

A guide to development partnerships produced by the British Equal Support Unit addresses individual and collective empowerment, on the principle that "those who have little or no influence, such as excluded people, are able to acquire the capacity to have informed opinions, to take initiatives, make independent choices and influence change"(Equal Support Unit, 2004, p6). Individual empowerment is concerned with quality of life, employment opportunities, participation and personal development (including confidence, motivation, self-respect, self-identity, organisational skills, independence, and taking initiative). At the group level, empowerment includes personal development through team working, and aspects of group functioning such as group development (for example mutual support and agenda sharing), capacity (such as organisational and leadership roles) and representation (for example project management and negotiation skills).

The empowerment literature therefore may provide a framework on which future investigations, for example longitudinal ethnographic or case studies, could be based.

As well as drawing on other models in order to further research into this area, future investigations should aim to consolidate and extend the findings and issues raised by the current study. Since the group of people who took part in this study constituted a non-randomised sample, further research with a larger representative group of individuals is needed to establish generalisability and validity of the findings of this study. This may take the form of a survey designed to obtain information pertaining to the themes generated by analysis of the interviews in this study. The analysis of associations between quantitative measures of psychosocial wellbeing, social involvement as well as instrumental and communicative use of the Internet may also be indicated, as a

means of specifying more objectively the implications of Internet use for people with HFA or AS. A longitudinal research design could give more indication of causal relationships, although as was evident in the review of literature pertaining to CMC, such studies are rarer. It may be difficult to control for confounding variables and to recruit participants who have no prior experience of CMC whatsoever. Although email use is a very prevalent use of the Internet, more synchronous forms of CMC are less widely used and may therefore be a suitable focus for longitudinal research.

One important aspect of the findings of this study which warrants further in depth investigation is the issue of personal vulnerability, and how participants manage this risk whilst benefiting from the liberating effects online communication may bring them (for a study of this issue as it pertains to people with physical or sensory difficulties see Bowker & Tuffin, 2003). A qualitative investigation of this type could provide valuable information for people with AS or HFA and their families, as well as relevant professionals and service providers.

Further research should also encompass the perspectives of high-functioning autistic individuals with respect to newer aspects of Internet-based communication which have become more prominent during the course of this study, for example the use of social networking sites, webcams and blogs. Also, given that one benefit of Internet communication was the potential to control one's availability to others, the implications of the proliferation of mobile phone and Internet access, bringing more interruptions and a higher cognitive load, merit further investigation.

This piece of research has raised aspects of communication media which influenced participants' perceptions of effectiveness. Controlled experiments similar to some of those discussed in Chapter 3 (for example Bargh et al., 2002; Hancock & Dunham, 2001; McKenna, et al., 2002; Nowak et al., 2005), could provide further evidence to substantiate these perceptions, for example comparisons between performances in different media (telephone, instant messaging, email, face-to-face, videoconferencing), with respect to communicative effectiveness, conversational structure, interpersonal dynamics, self-disclosure, intimacy and impression formation. The existent research of this type was carried out by Rajendran and Mitchell (2006) and involved a very specific route solving task. Individuals with AS were equally competent in solving the task by telephone or by text chat, but less adept than a typically

developing control group. There is a lot of potential to expand this research direction.

Experimental research should also include studies of interactions between people on the autistic spectrum as well as those between neurotypical and autistic individuals. The issue of anonymity is a variable which should be incorporated into experimental research of this nature, as well as investigations of group communication in contrast to communication between two individuals. Experimental studies such as this may address the issue of whether online communication can enable people with HFA or AS to communicate in a way which disadvantages them less in their interactions with others, and also with regard to how they are perceived. Another aspect which was raised by the participants in this study, and which may be appropriate for further investigation, was the better control they felt over their emotions when communicating online compared to in person. Perhaps comparisons of biometric measurements of emotional responses between on and offline settings would elucidate further this perceived benefit.

The findings of this piece of research are based on reports obtained from research participants. There is a need to complement this approach with the use of naturalistic observational methods for example the analysis of discussions from online forums for people on the autistic spectrum, focusing on aspects such as communicative functions, group dynamics, conversational structure and social norms. The small amount of research involving analysis of online groups for people with HFA or AS has focused on content rather than on communicative aspects (see Brownlow & O'Dell, 2006).

Although this study has highlighted the potential benefits of CMC for people with HFA or AS, knowledge which may be advanced by the suggested directions outlined above, it has not addressed the implications for autistic people who are less able than the current research participants. Further exploratory research into their social and communicative needs, as well as their uses and gratifications regarding the Internet, is indicated. This may provide useful information which could guide the design of interfaces adapted to address their particular cognitive, perceptual and social needs. For accounts of the design and effects of an adapted email interface for people with severe cognitive impairments, see Todis et al (2005) and Sohlberg et al (2005).

Practical applications

This study has identified the inclusive potential of the Internet for people at the high-functioning end of the autistic spectrum. The Internet is an established feature of the developed world, and its penetration into people's the everyday lives continues to grow. However some sections of the population are disadvantaged in their access to the Internet, for example people of low income and people with disabilities. People with HFA or AS are therefore more likely to be excluded from accessing the Internet, and the opportunity to alleviate their difficulties with social interaction and communication. The proportion of respondents to the survey who accessed the Internet at home was lower than in the general population (Dutton & Helsper, 2007) implying that access was less available to this group.

One implication of this piece of research is that service providers and policy makers need to consider the role of improved Internet access in enhancing the participation of high-functioning autistic people within education, employment and social networks, whilst being mindful of potential risks. There are also clinical implications. The role of CMC in the provision of support and counselling should be explored, in particular cognitive behavioural therapy which has emerged as particularly suitable for people on the autistic spectrum, as well as the online format. As well as affording people with HFA or AS an alternative mode of communication by which to access therapeutic counselling, the Internet may also provide a structured environment in which to learn new social skills and gradually transfer them to offline situations a suggestion made by Amichai-Hamburger and Furnham (2007). They propose a model in which socially inhibited people progressively lose the feeling of total control which they experience online and equip themselves to cope with the relative loss of control in offline situations. This is achieved through a series of steps from text only communication, moving on to text and live video image, then communication by video and audio, and finally face-to-face interaction. The evaluation of this approach for people at the high-functioning end of the autistic spectrum merits further investigation.

It would also be appropriate to consider whether the wider availability of online communication would improve access for people with AS or HFA to other primary and secondary clinical services, by making it easier for them to make initial approaches. Additionally, from personal experience I would strongly recommend that researchers, and other professionals who need to engage in dialogue with people at the high-functioning end of the autistic spectrum,

consider Internet-based communication as a means by which individuals may participate more actively and express their opinions and needs more effectively, with implications for self-advocacy.

Concluding statement

This study constitutes an exploration of the use of the Internet as a communication medium by people with high-functioning autism or Asperger syndrome, an area into which there had been little research previously. It has provided a rich and detailed description of this phenomenon as experienced by a sample of people with HFA or AS. It has shown the ways in which people at the high-functioning end of the autistic spectrum may capitalise on the serendipitous benefits of the Internet to address their communication needs and break down some of the social barriers which permeate their lives.

The accounts of the participants have generated a vivid picture of their experiences of social communication both on and offline. In particular, they have described the overwhelming lack of control which may occur for them when attempting to engage in more direct forms of communication, and explored how this may be lessened when communicating via the Internet. The visual anonymity, flexible timing and permanent nature of the Internet serve to diminish the social, emotional and time pressures of interpersonal communication and also the cognitive complexity of the processes involved. The drive for greater control over social communication was a major motivation for the use of the Internet.

However, although the loss of nonverbal cues online is one way in which the social and cognitive load of interpersonal interactions can be lessened, there is some ambivalence regarding this aspect of communication more generally. The potential of an absence of visual cues to reduce the cognitive demands of communication may be offset by the challenges of synchronous or auditory aspects, which characterise traditional forms of communication such as the telephone. There is an inference that at least at a basic level people with HFA or AS gain some benefit from visual cues to emotional status and structural aspects of conversation such as turn taking. Therefore Internet-mediated communication is not without its limitations.

This study has also shown that the social impairment of autism is not necessarily characterised by a lack of desire for contact with other people. By using the Internet people with AS or HFA may extend their opportunities to relate to other people on terms which are perhaps more suited to their

individual social and communication needs. As well as being able to interact in a potentially less stressful situation, individuals are afforded more possibilities and choices to expand their social networks. Online forums with rules and moderation could also provide structure and guidance for social interaction in a group situation.

The Internet therefore may be liberating in its effects for individuals at the high-functioning end of the autistic spectrum, expanding the potential to explore and express their identities, and opening up possibilities in terms of access to employment, education, social interaction and support. Although their experiences and perceptions of the Internet as a communication medium were largely positive, interviewees also raised the negative aspects of losing self-control when online, as well as the risks of communicating with unseen or unknown people.

As discussed earlier in this thesis, despite being of normal or superior intelligence people with AS or HFA are subject to social disadvantage. With respect to employment they are arguably a wasted resource; there is a loss to society as well as the individual as a result of their poor employment prospects. On a personal level there are risks of economic disadvantage, social isolation, marginalisation, and psychological problems such as low self-esteem, stress, anxiety and depression. It seems imperative that the potential of the Internet to bypass or lessen some of the social barriers of their everyday lives is acknowledged and acted upon.

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LIST OF APPENDICES

Appendix A

Letter to "gate keepers" seeking survey respondents

University of Nottingham
School of Community Health Sciences
ADRU
B Floor, The Medical School
Queens Medical Centre
Nottingham
NG7 2UH

4 May 2004

xxxxxxxxxx
xxxxxxxxxxxxxxx
xxxxxxxxxxxxxxxx
xxxxxxx xxxxxx

Dear xxxxxxxx

AUTISM AND INTERNET RESEARCH

I am writing to you to ask if you would be able to help me with a research project. I am a PhD student in the School of Community Health at the University of Nottingham and am studying how and why the Internet is, or is not, being used by people with high functioning autism or Asperger syndrome. I am particularly interested in how it is being used as a communication medium.

As a first step into my investigation I am looking for adults (16 years and over) with a diagnosis of Asperger syndrome or high functioning autism, who would be prepared to complete a confidential questionnaire about their use of computers and the Internet, as well as other questions about their hobbies, leisure and communication in general.

As a professional who is involved with this group of people, I wonder if you would be able to help me get in touch with individuals who would be willing to complete the questionnaire? If you are in a position to help, there is a choice of options by which we may proceed, depending on your particular requirements:

7 The questionnaires, and prepaid envelopes for their return, could be sent to you to be distributed as you feel appropriate.

or

8 I could send some fliers calling for expressions of interest which could be distributed. Anyone interested could then contact us by phone, letter, email, or fax and be sent the questionnaire with prepaid envelope.

or

9 I could visit you and meet with potential questionnaire respondents to give information about the study, answer any questions and distribute questionnaires, with prepaid envelopes for return.

The questionnaire is available as a webpage if that is more convenient.

I should emphasise that as well as hearing from those who do use the Internet, information from those who do not is also very valuable to help me understand the picture more fully.

For your information, I enclose a copy of the Information Sheet which would be given to volunteers.

Any help you could offer would be very valuable and greatly appreciated. If you would like to be involved and/or have any queries about this please do contact me, Penny Benford, on 0115 9709247 or email mcxpb@nottingham.ac.uk.

With thanks

Penny Benford
PhD Student

Appendix B

Poster/flier advertising for survey respondents

HAS THE INTERNET CHANGED YOUR LIFE, OR ARE YOU JUST NOT INTERESTED? YOUR VIEWS ARE VALUABLE

I am a PhD student, keen to hear from adults (16 years old and over) with a diagnosis of Asperger syndrome or high functioning autism, who would like to take part in a project investigating how and why they are, or are not, using the Internet.

I am looking for volunteers to complete a questionnaire about their use of computers and the Internet, as well as their hobbies, leisure and use of other forms of communication. The questionnaire can be sent by post (with a prepaid envelope for its return) or is available as a web page if more convenient. All information gathered will be kept confidential.

Again I would emphasise that it is important for me to hear both from people who do use the Internet and from those who do not.

If you would be willing to help, or would like further information, please write, phone, fax or email with your name and contact details:

The University of Nottingham

Penny Benford
University of Nottingham
School of Community Health Sciences
ADRU
B Floor, The Medical School
Queens Medical Centre
Nottingham
NG7 2UH
Tel: 0115 8466382
Fax: 0115 9423618
Email: mcxpb@nottingham.ac.uk

Appendix C

Press release advertising for survey respondents

HAS THE INTERNET CHANGED YOUR LIFE, OR ARE YOU JUST NOT INTERESTED? YOUR VIEWS ARE VALUABLE

I am a PhD student at the University of Nottingham and am keen to hear from adults (16 years old and over) with a diagnosis of Asperger syndrome or high functioning autism, who would like to take part in a project investigating how and why they are using the Internet. I am particularly interested in how it is, or is not, being used as a means of communication.

I am looking for a fairly large number of volunteers who would be willing to provide me with their names and addresses. You would then be sent a questionnaire and a freepost envelope for its return after completing it should you decide to do so. The questionnaire will be available as a webpage if that is more convenient.

The questionnaire would include questions about your use of computers and the Internet as well as other questions about yourself including hobbies, leisure and communication in general. All information gathered would be kept confidential.

Again I would emphasise that as well as hearing from people who do use the Internet, information from those who do not is also very valuable to help me understand the situation more fully.

If you would be willing to help, or would like further information, please write, phone, fax or email with your name and contact details:

Penny Benford
University of Nottingham
School of Community Health Sciences
ADRU
B Floor, The Medical School
Queens Medical Centre
Nottingham
NG7 2UH

Tel: 0115 8466382
Fax: 0115 9423618
Email: mcxpb@nottingham.ac.uk

Appendix D

Survey questionnaire

INTERNET QUESTIONNAIRE

PART 1

HOBBIES AND LEISURE ACTIVITIES

1 What are the things you like to do during your spare time?

Please list up to 3 activities in order of preference.

1.
2.
3.

2 Do you belong to any clubs or groups which are **not** based on the Internet?

Yes ☐

No ☐

If you answered yes please go to question 3
If you answered no please go to question 4

3 Approximately how often do you take part in meetings or activities organised by the clubs or groups you belong to?

More than 3 times a week ☐

2 or 3 times a week ☐

Once a week ☐

Once every 2 weeks ☐

Once a month ☐

Less than once a month ☐

Never ☐

4 How often do you spend time with friends in situations not organised by a club or group?

More than 3 times a week ☐

2 or 3 times a week ☐

Once a week ☐

Once every 2 weeks ☐

Once a month ☐

Less than once a month ☐

Never ☐

COMMUNICATING WITH PEOPLE

5 How do you like to communicate with friends?

Below is a list of different ways of communicating with friends. Please show how much you like or don't like each one by ticking the appropriate box.

	Like it a lot	**Like it a little**	**Don't like it**
Face-to-face contact	☐	☐	☐
Email	☐	☐	☐
Letters	☐	☐	☐
Telephone call	☐	☐	☐
Live online chat	☐	☐	☐
Text messaging	☐	☐	☐

6 How do you like to communicate with other people who are **not** friends?

Below is a list of different ways of communicating with other people who are not friends. Please show how much you like or don't like each one by ticking the appropriate box.

	Like it a lot	**Like it a little**	**Don't like it**
Face-to-face contact	☐	☐	☐
Email	☐	☐	☐
Letters	☐	☐	☐
Telephone call	☐	☐	☐
Live online chat	☐	☐	☐
Text messaging	☐	☐	☐

ABOUT YOU

Please tick the age group you fit into.

16 – 19 ☐

20 – 29 ☐

30 – 39 ☐

40 – 49 ☐

50 – 59 ☐

60 – 69 ☐

70 and over ☐

8 What is your sex?

Male ☐

Female ☐

9 What is your current marital status?

Single (never married) ☐

Married ☐

Divorced or separated ☐

Living with partner ☐

Widowed ☐

What is your ethnic background?

White British ☐

Mixed background ☐

Asian ☐

Black Caribbean ☐

Black African ☐

Chinese ☐

Other ☐

Which of these qualifications do you have? Please tick all the qualifications below which apply to you.

1 or more O levels/CSEs/GCSEs……. ☐

5 or more O levels/CSEs/GCSEs……. ☐

1 or more A levels…… ☐

First degree (eg BA, BSc)…… ☐

Higher degree (eg MA, PhD, PGCE, postgraduate certificate or diploma) ☐

NVQ Level 1, Foundation GNVQ……... ☐

NVQ Level 2, Intermediate GNVQ……. ☐

NVQ Level 3, Advanced GNVQ……. ☐

NVQ Level 4-5, HNC, HND…… ☐

No qualifications…….. ☐

Other **(please give details in the box provided)**

☐

Are you currently in fulltime education?

Yes ☐

No ☐

If you answered <u>yes</u> please go to question 16 (on the next page)
If you answered <u>no</u> please go to question 13 (on the next page)

13 Do you have a job?

Yes ☐

No ☐

If you answered <u>yes</u> please go to question 14
If you answered <u>no</u> please go to question 16

14 Please write down your job title or describe the type of work you do in your job

15 Could your job be described as any of the following?

Sheltered employment ☐

Supported employment ☐

Voluntary work ☐

Government sponsored training scheme ☐

None of the above ☐

16 Which of the following best describes where you live?

I live with one or more members of my family ☐

I live on my own ☐

I share a house or flat with friends ☐

I live in supported accommodation ☐

I live in a group home ☐

Other **(please give details in the box provided)** ☐

17 How old were you when you were diagnosed as having an autistic spectrum disorder?

Less than 10 years old ☐

10 to 15 years old ☐

16 to 20 years old ☐

21 to 30 years old ☐

31 to 40 years old ☐

41 to 50 years old ☐

More than 50 years old ☐

Don't know ☐

USING COMPUTERS

Have you ever used computers?

Yes ☐

No ☐

If you answered <u>yes</u> please go to question 19
If you answered <u>no</u> please go to question 20

19 Do you still use computers?

Yes ☐

No ☐

If you answered <u>yes</u> please go to part 2 on the yellow pages
If you answered <u>no</u> please go to question 20 below

20 Please give the reason(s) why you do not use computers. Tick those reasons below which apply to you.

I have not been taught how to use computers ☐

I do not like computers ☐

I have no reason to use computers ☐

I do not want to use computers ☐

There are physical/medical reasons which make it difficult for me to use computers ☐

It is not easy for me to get to places where I could use a computer ☐

I do not have a computer at home ☐

Other **(Please explain in box provided)** ☐

Now please go to page 17 which is purple.

PART 2

MORE ABOUT COMPUTERS

In which of the following places do you use computers? Please tick those which apply to you.

At home	☐
At work	☐
At school, college or university	☐
At a public library	☐
At an Internet café	☐
At someone else's home	☐
Other **(Please give details in box provided)**	☐

22 How often do you do the following computer activities? Please show how often you do each activity by ticking the appropriate box.

	Frequently	**Rarely**	**Never**
Accessing the Internet	☐	☐	☐
Sending email	☐	☐	☐
Playing games	☐	☐	☐
Creating documents, letters etc	☐	☐	☐
Keeping accounts and financial records	☐	☐	☐
Storing information and records	☐	☐	☐
Developing software	☐	☐	☐
Storing digital photographs	☐	☐	☐
Artistic and/or media production	☐	☐	☐
Watching DVDs	☐	☐	☐
Learning or training courses	☐	☐	☐
Other **(Please give details in the box provided)**	☐	☐	☐

How much time per week do you spend using the computer for work or studying?

None ☐

Less than 1 hour per week ☐

1 hour to less than 2 hours per week ☐

2 hours to less than 4 hours per week ☐

4 hours to less than 10 hours per week ☐

10 hours to less than 20 hours per week ☐

20 hours to less than 30 hours per week ☐

More than 30 hours per week ☐

24 How much time per week do you spend using the computer for leisure purposes (not for work or studying)?

None ☐

Less than 1 hour per week ☐

1 hour to less than 2 hours per week ☐

2 hours to less than 4 hours per week ☐

4 hours to less than 10 hours per week ☐

10 hours to less than 20 hours per week ☐

20 hours to less than 30 hours per week ☐

More than 30 hours per week ☐

25 How much do you agree or disagree with the following statement?

I would like to be able to use computers more than it is possible for me to do so at the moment.

strongly agree ☐ agree ☐ disagree ☐ strongly disagree ☐

USING THE INTERNET

26 Have you ever used the Internet (including email)?

Yes ☐

No ☐

If you answered yes please go to question 27
If you answered no please go to question 28

27 Do you still use the Internet?

Yes ☐

No ☐

If you answered yes please go to Part 3 which is green
If you answered no please go to question 28 on the next page

28 Please give the reason(s) why you do not use the Internet. Tick those reasons below which apply to you.

I have not been taught how to use the Internet	☐
I do not like the Internet	☐
I have no reason to use the Internet	☐
I do not want to use the Internet	☐
It is not easy for me to get to places where I could access the Internet	☐
I do not have Internet access at home	☐
Other **(Please explain in the box provided)**	☐

Now please go to page 17 which is purple.

PART 3

MORE ABOUT THE INTERNET

29 How old were you when you first started using the Internet?

Less than 10 years old	☐
11 - 15 years old	☐
16 - 20 years old	☐
21 - 30 years old	☐
31 – 40 years old	☐
41 – 50 years old	☐
More than 50 years old	☐

30 In which of the following places do you use the Internet? Please tick those which apply to you.

At home	☐
At work	☐
At school, college or university	☐
At a public library	☐
At an Internet café	☐
At someone else's home	☐
Other **(Please give details in the box provided)**	☐

31 How often do you do the following Internet activities? Please show how often you do each activity by ticking the appropriate box.

	Frequently	**Rarely**	**Never**
Sending or receiving email	☐	☐	☐
Getting news online.	☐	☐	☐
Shopping online	☐	☐	☐
Online education or training courses	☐	☐	☐
Getting travel information	☐	☐	☐
Getting holiday information	☐	☐	☐
Looking for jobs	☐	☐	☐
Booking travel or holiday services	☐	☐	☐
Research for work or study purposes	☐	☐	☐
Looking for health or medical information	☐	☐	☐
Checking weather reports and forecasts	☐	☐	☐
Checking sports scores and information	☐	☐	☐
Looking for information about a hobby or interest	☐	☐	☐
Taking part in chat rooms or online discussions with other people	☐	☐	☐
Banking online	☐	☐	☐
Playing games online	☐	☐	☐
Listening to or downloading music	☐	☐	☐
Watching video clips or audio clips	☐	☐	☐
Building, creating and working on World Wide Web (WWW) Pages	☐	☐	☐
Going online for no particular reason, just for fun or to pass the time	☐	☐	☐
Other **(please give details in the box provided)**	☐	☐	☐

32 Approximately how much time do you spend on the Internet per week?

Less than 1 hour per week ☐

1 hour to less than 2 hours per week ☐

2 hours to less than 4 hours per week ☐

4 hours to less than 10 hours per week ☐

10 hours to less than 20 hours per week ☐

20 hours to less than 30 hours per week ☐

More than 30 hours per week ☐

33 How much do you agree or disagree with the following statement?

I would like to be able to use the Internet more than it is possible for me to do so at the moment.

strongly agree ☐ agree ☐ disagree ☐ strongly disagree ☐

COMMUNICATING WITH OTHER PEOPLE OVER THE INTERNET

34 Have you ever used the Internet to communicate with other people (including email)?

Yes ☐

No ☐

If you answered yes please go to question 35
If you answered no please go to question 36

35 Do you still use the Internet to communicate with other people (including email)?

Yes ☐

No ☐

If you answered yes please go to question 37 on the next page
If you answered no please go to question 36 below

36 Please give the reason(s) why you do not use the Internet to communicate with other people. Tick those reasons below which apply to you.

I have not been taught how to use the Internet to communicate with other people ☐

I do not like using the Internet to communicate with other people ☐

I have no reason to use the Internet to communicate with other people ☐

I do not want to use the Internet to communicate with other people ☐

Other **(Please explain in the box provided)** ☐

Now please go to page 17 which is purple.

MORE ABOUT COMMUNICATING OVER THE INTERNET

37 How often do you do the following Internet activities? Please show how often you do each activity by ticking the appropriate box.

	Frequently	Rarely	Never
Exchange emails with family/friends	☐	☐	☐
Exchange emails with other people for work or study purposes	☐	☐	☐
Exchange emails with other people who are not family or friends, for non-work purposes (eg to make enquiries, arrangements or bookings)	☐	☐	☐
Take part in chat rooms or online discussions	☐	☐	☐
Take part in multi user domains (MUDS)	☐	☐	☐
Exchange emails with online groups (newsgroups, bulletin boards, discussion lists and mailing lists)	☐	☐	☐

Approximately how much time do you spend communicating with other people over the Internet per week?

Less than 1 hour per week ☐

1 hour to less than 2 hours per week ☐

2 hours to less than 4 hours per week ☐

4 hours to less than 10 hours per week ☐

10 hours to less than 20 hours per week ☐

20 hours to less than 30 hours per week ☐

More than 30 hours per week ☐

39 If you take part in chat rooms or online groups this question is for you. Otherwise please go to question 40 on the next page.

Please indicate how much you agree or disagree with <u>each</u> of the following statements:

39a I take part in online groups or chat rooms because it enables me to make contact with people who have similar hobbies or interests to mine

strongly agree ☐ agree ☐ disagree ☐ strongly disagree ☐

39b I take part in online groups or chat rooms because I enjoy this way of communicating with other people

strongly agree ☐ agree ☐ disagree ☐ strongly disagree ☐

39c I take part in online groups or chat rooms because I can make contact with other people who have an autistic spectrum disorder

strongly agree ☐ agree ☐ disagree ☐ strongly disagree ☐

39d I take part in online groups or chat rooms so I can find out information

strongly agree ☐ agree ☐ disagree ☐ strongly disagree ☐

39e I take part in online groups or chat rooms as a way of getting advice about a problem

strongly agree ☐ agree ☐ disagree ☐ strongly disagree ☐

39f I take part in online groups or chat rooms to meet new people

strongly agree ☐ agree ☐ disagree ☐ strongly disagree ☐

39g I take part in online groups or chat rooms because it makes me feel part of a community

strongly agree ☐ agree ☐ disagree ☐ strongly disagree ☐

39h I tend to take part in the same online groups or chat rooms

strongly agree ☐ agree ☐ disagree ☐ strongly disagree ☐

40 How much would you miss communicating with people over the Internet if you could no longer use it?

A lot ☐

A little ☐

Not much ☐

Not at all ☐

Now please go to page 17 which is purple

Thank you very much for filling in this questionnaire, your help is very valuable to us.

Please finish by looking at this last page and complete it if appropriate, and then return the whole booklet in the prepaid envelope.

Would you like to receive information about the results of this study?

Please sign below if you would like us to send you a summary of the results of this study.

I would like to receive a summary of the results of this study.

Name:……..……

Signature……**Date**:…….

Address…….

……..

……

…

Could we send you a second questionnaire?

As mentioned in the information sheet, it would be helpful to gather, by a second questionnaire, information about those features of high functioning autism or Asperger syndrome which affect your life. You are not obliged to receive the second questionnaire because you completed the first one. If you are able to help with this second questionnaire, please sign below it.

I agree to be sent the second questionnaire about high functioning autism or Asperger syndrome

Name:……..……

Signature…….**Date**:……..

Address……

…….

…….

Would you be willing to tell us some more about your experiences of communicating over the Internet?

In the future we would like to interview (by email if preferable) people with high functioning autism or Asperger syndrome, who use the Internet to communicate with other people, to gather more detailed information than is possible in a questionnaire. If you might be interested in taking part in this second project, please sign here to be contacted with further details at a later date. By agreeing to be contacted you are not committed to being involved in the second project, nor are you obliged to participate because you did the questionnaire.

I agree to be contacted about the possibility of being interviewed about Internet communication.

Name:……..…….

Signature…… **Date**:…….

Address……

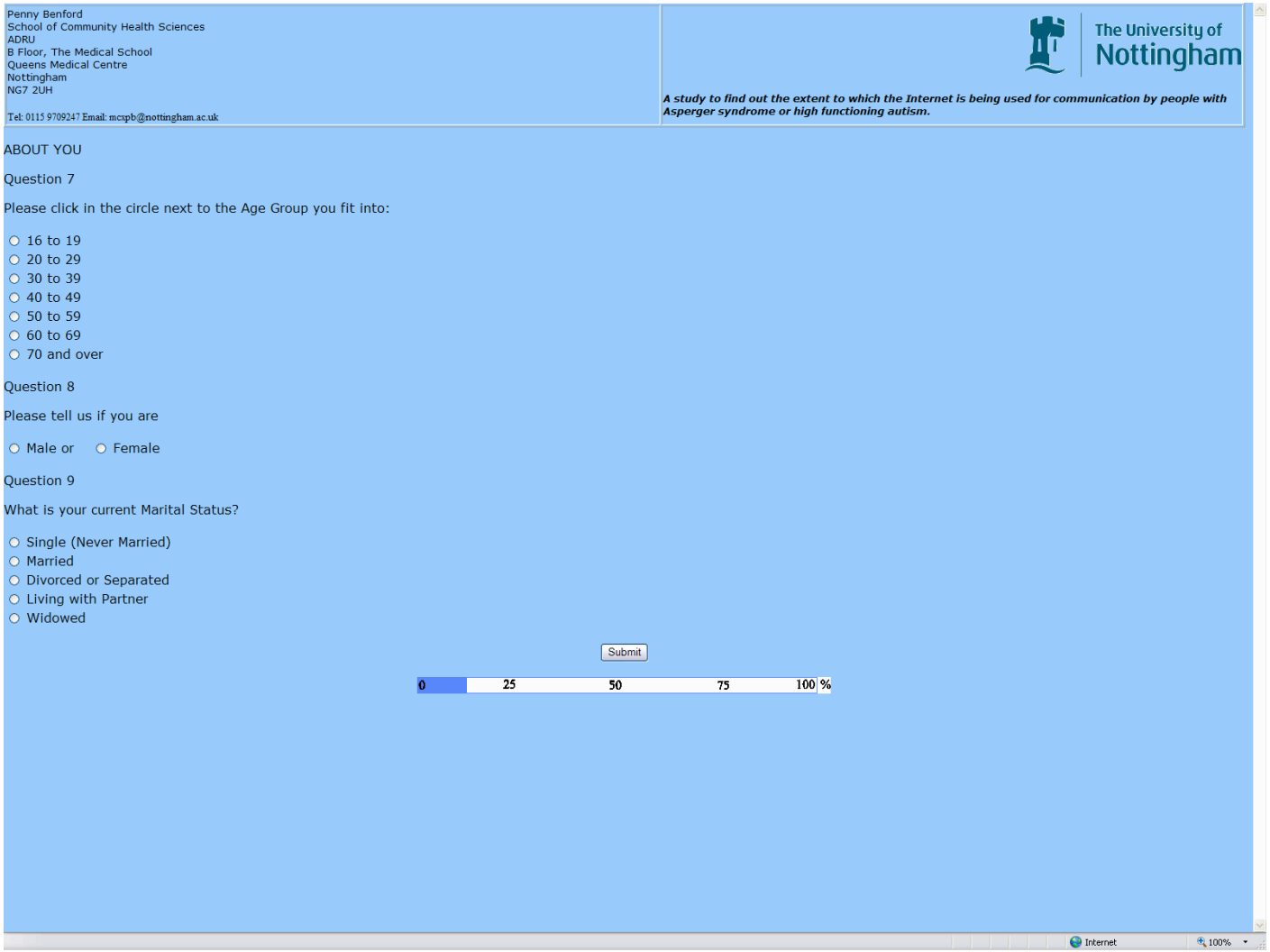
……

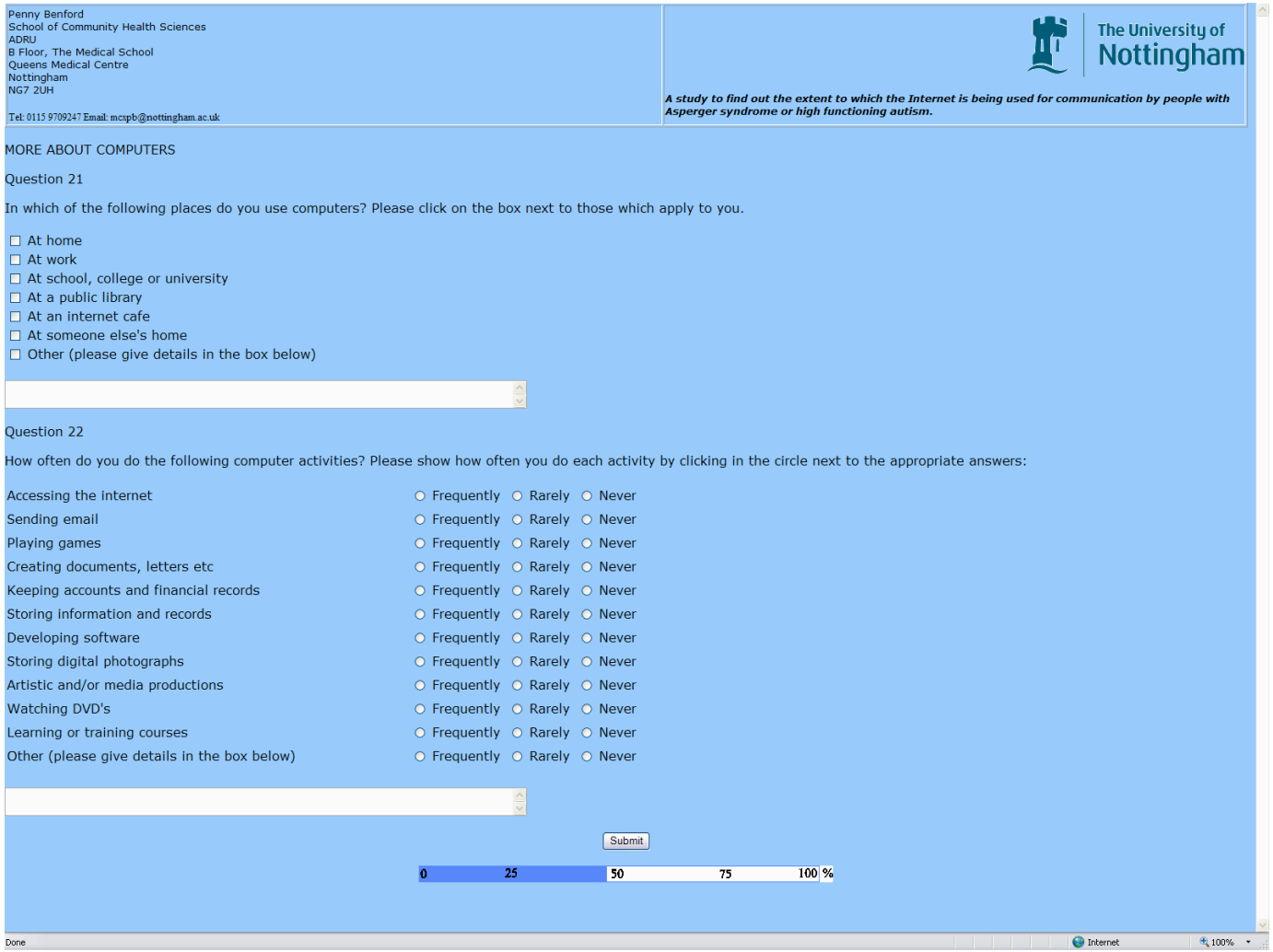
……...

Many thanks again for your help

Appendix E

Extracts from web version of survey questionnaire


Penny Benford
School of Community Health Sciences
ADRU
B Floor, The Medical School
Queens Medical Centre
Nottingham
NG7 2UH
Tel: 0115 9709247 Email: mcxpb@nottingham.ac.uk
The University of Nottingham
A study to find out the extent to which the Internet is being used for communication by people with Asperger syndrome or high functioning autism.
ABOUT YOU
Question 7
Please click in the circle next to the Age Group you fit into:
16 to 19
20 to 29
30 to 39
40 to 49
50 to 59
60 to 69
70 and over
Question 8
Please tell us if you are
Male or
Female
Question 9
What is your current Marital Status?
Single (Never Married)
Married
Divorced or Separated
Living with Partner
Widowed
Submit
0
25
50
75
100
%
Internet
100%



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The University of Nottingham

A study to find out the extent to which the Internet is being used for communication by people with Asperger syndrome or high functioning autism.

MORE ABOUT COMPUTERS

Question 21

In which of the following places do you use computers? Please click on the box next to those which apply to you.

- ☐ At home
- ☐ At work
- ☐ At school, college or university
- ☐ At a public library
- ☐ At an internet cafe
- ☐ At someone else's home
- ☐ Other (please give details in the box below)

Question 22

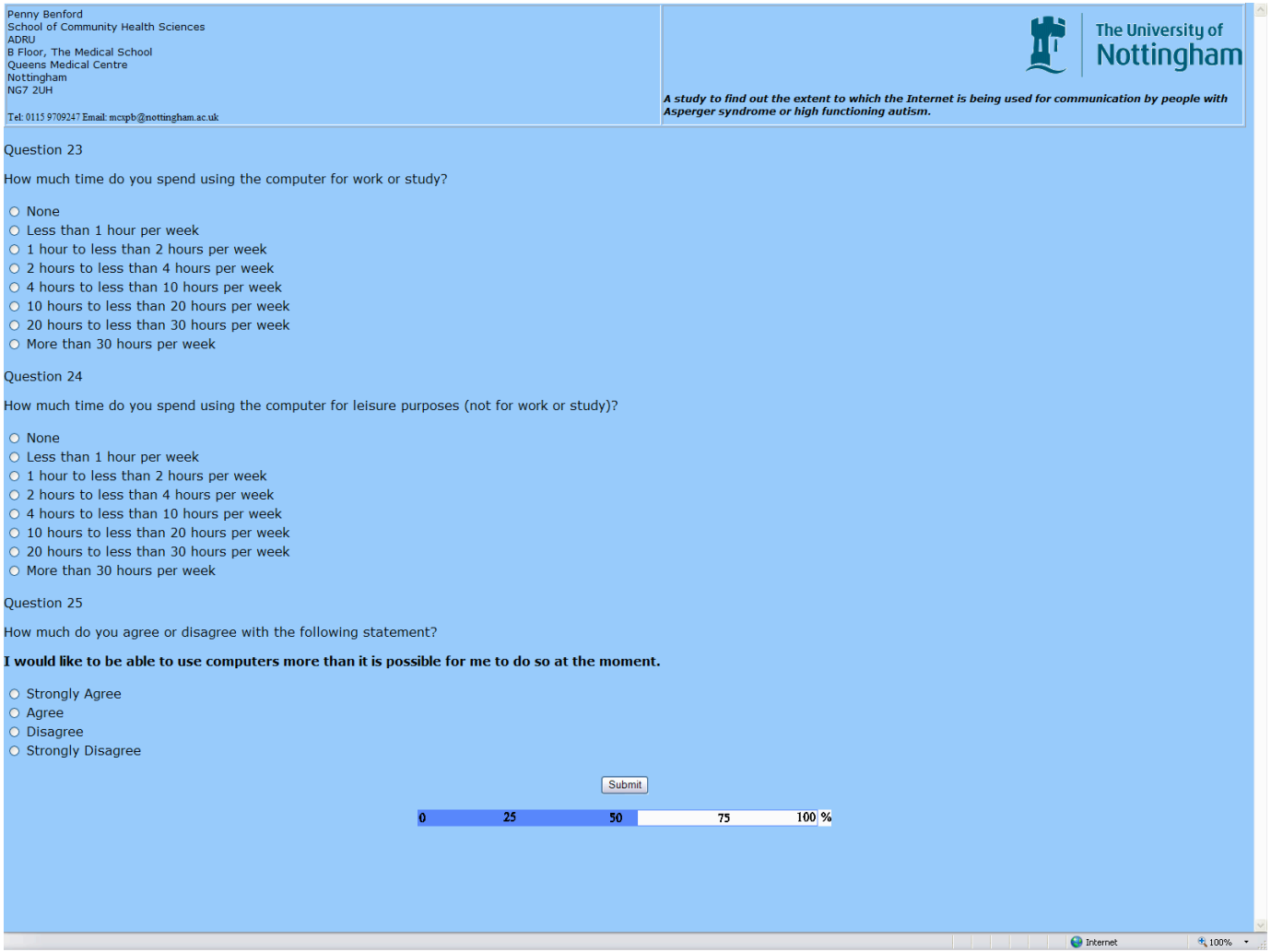
How often do you do the following computer activities? Please show how often you do each activity by clicking in the circle next to the appropriate answers:

Accessing the internet	○ Frequently	○ Rarely	○ Never
Sending email	○ Frequently	○ Rarely	○ Never
Playing games	○ Frequently	○ Rarely	○ Never
Creating documents, letters etc	○ Frequently	○ Rarely	○ Never
Keeping accounts and financial records	○ Frequently	○ Rarely	○ Never
Storing information and records	○ Frequently	○ Rarely	○ Never
Developing software	○ Frequently	○ Rarely	○ Never
Storing digital photographs	○ Frequently	○ Rarely	○ Never
Artistic and/or media productions	○ Frequently	○ Rarely	○ Never
Watching DVD's	○ Frequently	○ Rarely	○ Never
Learning or training courses	○ Frequently	○ Rarely	○ Never
Other (please give details in the box below)	○ Frequently	○ Rarely	○ Never

Submit

0 25 50 75 100 %

Done Internet 100%


Penny Benford
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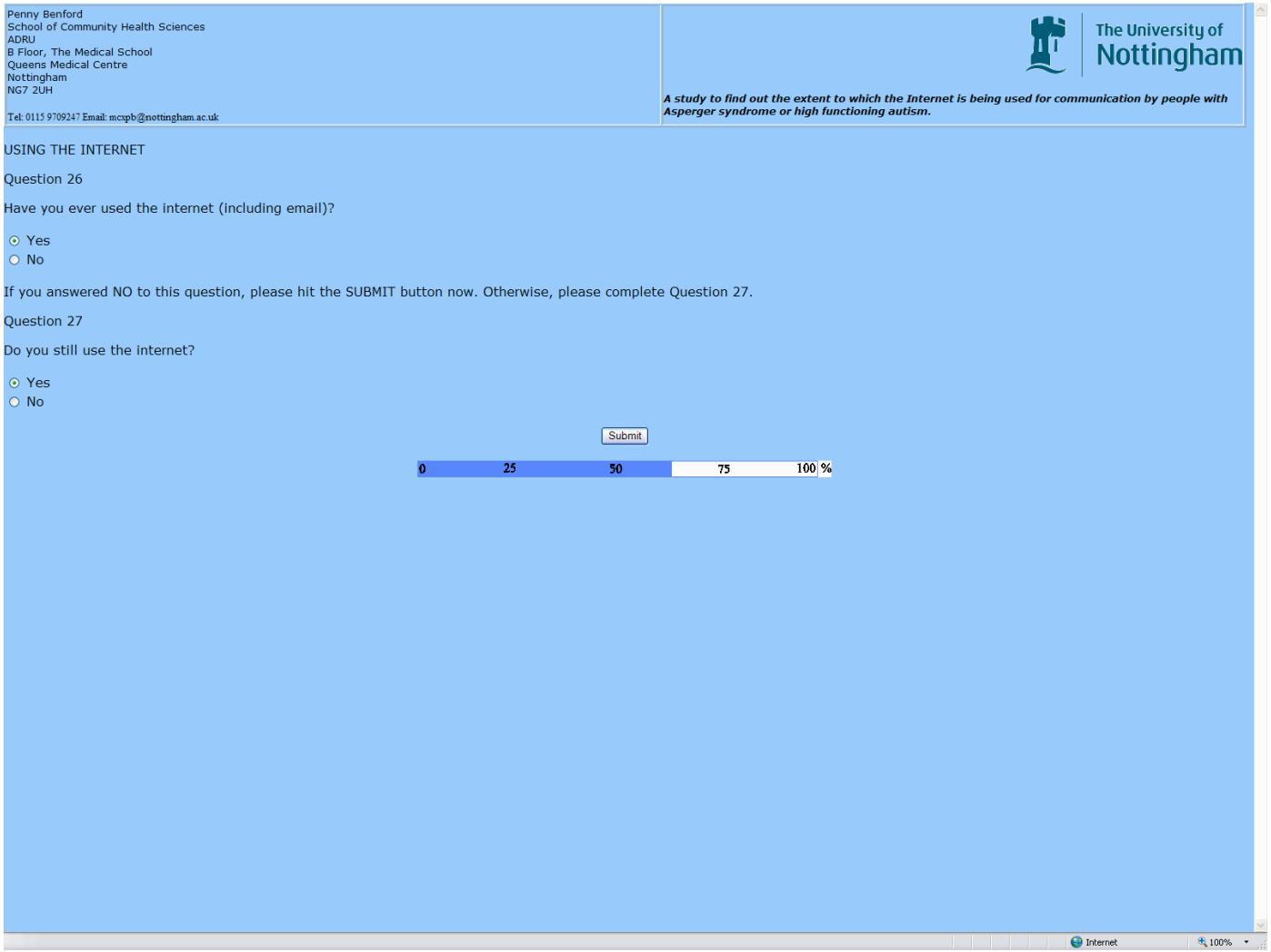
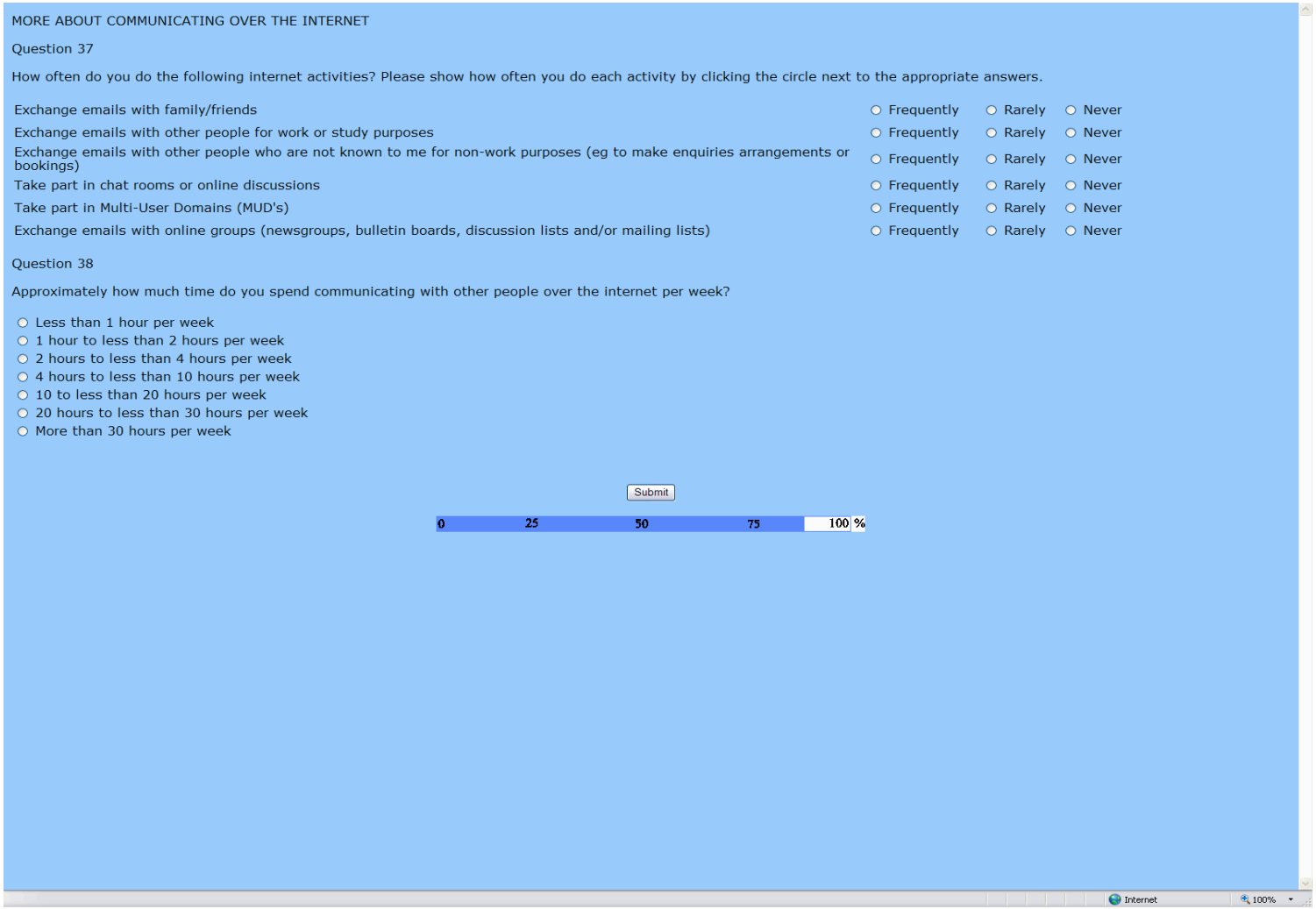
The University of Nottingham
A study to find out the extent to which the Internet is being used for communication by people with Asperger syndrome or high functioning autism.
Question 23
How much time do you spend using the computer for work or study?
None
Less than 1 hour per week
1 hour to less than 2 hours per week
2 hours to less than 4 hours per week
4 hours to less than 10 hours per week
10 hours to less than 20 hours per week
20 hours to less than 30 hours per week
More than 30 hours per week
Question 24
How much time do you spend using the computer for leisure purposes (not for work or study)?
None
Less than 1 hour per week
1 hour to less than 2 hours per week
2 hours to less than 4 hours per week
4 hours to less than 10 hours per week
10 hours to less than 20 hours per week
20 hours to less than 30 hours per week
More than 30 hours per week
Question 25
How much do you agree or disagree with the following statement?
I would like to be able to use computers more than it is possible for me to do so at the moment.
Strongly Agree
Agree
Disagree
Strongly Disagree
Submit
0 25 50 75 100 %
Internet
100%


Penny Benford
School of Community Health Sciences
ADRU
B Floor, The Medical School
Queens Medical Centre
Nottingham
NG7 2UH
Tel: 0115 9709247 Email: mcxpb@nottingham.ac.uk
The University of Nottingham
A study to find out the extent to which the Internet is being used for communication by people with Asperger syndrome or high functioning autism.
USING THE INTERNET
Question 26
Have you ever used the internet (including email)?
Yes
No
If you answered NO to this question, please hit the SUBMIT button now. Otherwise, please complete Question 27.
Question 27
Do you still use the internet?
Yes
No
Submit
0 25 50 75 100 %
Internet
100%



MORE ABOUT COMMUNICATING OVER THE INTERNET

Question 37

How often do you do the following internet activities? Please show how often you do each activity by clicking the circle next to the appropriate answers.

Exchange emails with family/friends	○ Frequently	○ Rarely	○ Never
Exchange emails with other people for work or study purposes	○ Frequently	○ Rarely	○ Never
Exchange emails with other people who are not known to me for non-work purposes (eg to make enquiries arrangements or bookings)	○ Frequently	○ Rarely	○ Never
Take part in chat rooms or online discussions	○ Frequently	○ Rarely	○ Never
Take part in Multi-User Domains (MUD's)	○ Frequently	○ Rarely	○ Never
Exchange emails with online groups (newsgroups, bulletin boards, discussion lists and/or mailing lists)	○ Frequently	○ Rarely	○ Never

Question 38

Approximately how much time do you spend communicating with other people over the internet per week?

- ○ Less than 1 hour per week
- ○ 1 hour to less than 2 hours per week
- ○ 2 hours to less than 4 hours per week
- ○ 4 hours to less than 10 hours per week
- ○ 10 to less than 20 hours per week
- ○ 20 hours to less than 30 hours per week
- ○ More than 30 hours per week

Submit

0 25 50 75 100 %

Appendix F

Information sheet for survey respondents

University of Nottingham
School of Community Health Sciences
ADRU
B Floor, The Medical School
Queens Medical Centre
Nottingham NG7 2UH

Healthy Volunteers Information Sheet

Title of Project: A study to find out the extent to which the Internet is being used for communication by people with Asperger syndrome or high functioning autism.

Investigators: Penny Benford, PhD student
Penny Standen, Reader in Health Psychology
Nicola Gray, Lecturer in Pharmacy Practice

Thank you for your interest in this research study. This information sheet is provided to explain why the research is being done and what it will involve so that you can decide whether or not to take part. Please take time to read it carefully and to discuss it with others if you wish to do so. Do contact me if there is anything that is not clear or if you would like more information. Thank you for reading this.

What is the purpose of the study?

The introduction of the Internet seems to have encouraged some people with high functioning autism, or Asperger syndrome, to communicate with each other via chat rooms and bulletin boards. Studies of other types of groups indicate that social support does occur online, providing help, advice, support and information. Although it is suggested that online communication is welcomed by some people with high functioning autism, or Asperger syndrome, there is a lack of research into this area. As a first step, this study aims to find out how and why the Internet is, or is not, being used by people with Asperger syndrome or high functioning autism.

What does the study involve?

The study will involve filling in a questionnaire (to be returned by post or email as appropriate) about your use of computers and the Internet as well as other questions about yourself including hobbies, leisure and communication in general. It should not take longer than about 20 minutes to complete and indeed may take less time than this. If you would like to ask someone you know to help you go through the questionnaire please do so. At the end you will be asked if you would be willing to receive another questionnaire about those features of high functioning autism or Asperger syndrome which affect your life. This second questionnaire should take up to 30 minutes to complete. It will only be sent to you if you sign the appropriate form on the final page of the first questionnaire.

Why have I been chosen?

You have been approached as someone with high functioning autism or Asperger syndrome who is 16 years of age or over.

Do I have to take part?

Taking part in this research is entirely voluntarily. If you do decide to take part you are still free to withdraw at any time and without giving a reason.

What are the risks of taking part?

This should not be a negative experience for you. If for any reason you do not want to answer a question, please indicate this on the form or leave it blank.

What are the benefits of taking part?

Although there will be no immediate benefit to you, the information obtained will help clarify what significance the Internet has for people with high functioning autism or Asperger syndrome. If you would like us to send you a summary of the results of this study, please let us know by signing the relevant section on the final page of the questionnaire.

Will my information be kept confidential?

All information that is collected about you during the course of the research will be kept on a password-protected database and is strictly confidential. The anonymous questionnaires will be kept in a locked filing cabinet and only the University research team will have access to them. Any information about you that leaves the research unit will have your name and address removed from it so that you cannot be recognised from it.

What will happen to the results of the research study?

The results obtained during the research study will be analysed, written up and assessed. Some of the results may be published in professional journals but subjects will not be identified in any report or publication.

What should I do if I want to complain?

If you wish to complain, or have any concerns about any aspect of the way in which you have been approached or treated during the course of this research study, please contact Penny Standen (Tel: 0115 9709247, email: p.standen@nottingham.ac.uk) in the first instance. If no satisfactory outcome is achieved you should then contact:

The Chairman of the Ethics Committee Secretary
The Dean's Office
B Floor, The Medical School
Queen's Medical Centre
Nottingham NG7 2UH

Who has reviewed the study?

This study has been reviewed and approved by the University of Nottingham Medical School Ethics Committee.

Who should I contact for further information?

If you have any queries please contact:

Penny Benford (PhD Student)
University of Nottingham
School of Community Health Sciences
ADRU
B Floor, The Medical School
Queens Medical Centre
Nottingham NG7 2UH
Tel: 0115 9709247 Email: mcxpb@nottingham.ac.uk

Appendix G

Letter of ethical approval for survey

This document is not available

Appendix H

Interview questions sent by post to reluctant/non Internet users

Internet Research Project

We are very interested to hear your thoughts, experiences and opinions regarding the Internet as a communication medium. The following set of questions are designed to give you the opportunity to tell us about your views on the subject. When answering these questions, please write as much or as little as you feel necessary. If you need more space please continue on the back of the sheets.

1. Have you ever used the Internet (email, chat rooms, newsgroups or bulletin boards) to communicate with someone else?

If so please look at questions 2 - 7

If not please look at question 8 - 9

2. What were your reasons for trying out this way of communication?

3. What did you think of your experience of communicating via the Internet?

4. Did you want to carry on using this form of communicating? If so why?

5. If not, why not?

6. How do you think communicating via the Internet compares with other forms of communication (eg face to face, telephone, letters, text messaging)?

7. If there is anything else you would like to tell us about the Internet as a means of communicating, please do tell us.

FOR PEOPLE WHO HAVE NEVER USED THE INTERNET AS A MEANS OF COMMUNICATION:

8. Is communicating via the Internet something you may like to try one day?

If so, what would be your reasons for trying it out?

If not, what are reasons for not trying it out?

9. If there is anything else you would like to tell us about the Internet as a means of communicating, please do tell us.

Thank you very much for you help with this research. Please return your answers in the prepaid envelope provided. We will read your replies and may send one further letter containing follow up questions if this seems appropriate.

Appendix I

Information sheet for interview participants

University of Nottingham
School of Community Health Sciences
ADRU
B Floor, The Medical School
Queens Medical Centre
Nottingham NG7 2UH

Volunteer Information Sheet

Title of Project: A study to explore the experiences, motivations and perceptions of people with Asperger syndrome or high functioning autism who use the Internet for communication.

Investigators: Penny Benford, PhD student
Penny Standen, Professor of Health Psychology

Thank you for your interest in this research study. This information sheet is provided to explain why the research is being done and what it will involve so that you can decide whether or not to take part. Please take time to read it carefully and to discuss it with others if you wish to do so. Do contact me if there is anything that is not clear or if you would like more information. Thank you for reading this.

What is the purpose of the study?
This study follows on from a survey carried out by the investigators which found that Internet communication (via email, chat rooms, newsgroups and bulletin boards) is welcomed by some people with high functioning autism or Asperger syndrome. It aims to gather information about people's individual experiences and opinions of Internet communication, in more detail than was possible in a questionnaire.

What does the study involve?
The study will involve being interviewed by email about your experiences of using the Internet, your opinions and thoughts on it as a communication medium, the effect you feel it has had, if any, on your life and how you contact other people. At the beginning of the study you will be sent a list of topics as a guide to the type of questions you may receive. However this is merely a guide, and there will be the flexibility for discussion of other relevant topics which may not appear on the list. Because of this, and because of the "open nature" of the questions (to allow for you to expand on what you would like to say, rather being restricted to giving a short specific answer), it is hard to say how long the process will take. It will depend in part on what you would like to tell us and how quickly emails are exchanged between us. However it is envisaged that the interview will take place over several emails, which you can answer at your convenience. As a rough guide this may take a few days or weeks

(For more detailed information please refer to **"Email interview process and broad topic guide"***)*

Why have I been chosen?
You have been approached as someone with high functioning autism or Asperger syndrome who is 16 years of age or over, and who uses the Internet as a means of communicating with other people. We are contacting you in response to your expression of interest in being involved in this study, either on the questionnaire returned to us from the first part of this study or via the moderator of an online group of which you are a member.

Do I have to take part?
Taking part in this research is entirely voluntarily. If you do decide to take part you are still free to withdraw at any time and without giving a reason.

What are the risks of taking part?
This should not be a negative experience for you. If for any reason you do not want to answer a question, please indicate this in your email reply.

What are the benefits of taking part?
Although there will be no immediate benefit to you, the information obtained will help clarify what significance the Internet has for people with high functioning autism or Asperger syndrome, in particular which of its features, if any, make it a comfortable communication medium, features which should be retained in the face of changes in technology. We will be very happy to send you a summary of the results of the study if you would like one.

Will my information be kept confidential?
All information that is collected about you during the course of the research will be kept on a password-protected database and is strictly confidential. Paper documents will be kept in a locked filing cabinet and only the research team will have access to them. Any information about you that leaves the research unit will have your name and address or other personally identifying information removed from it so that you cannot be recognised.

What will happen to the results of the research study?
The results obtained during the research study will be analysed, written up and assessed. Some of the results may be published in professional journals but participants will not be identified in any report or publication. Extracts from your interviews may be used to illustrate reports but will not contain any information that may identify you.

What should I do if I want to complain?
If you wish to complain, or have any concerns about any aspect of the way in which you have been approached or treated during the course of this research study, please contact Penny Standen (Tel: 0115 8230233, email: p.standen@nottingham.ac.uk) in the first instance. If no satisfactory outcome is achieved you should then contact:

The Chairman of the Ethics Committee Secretary
The Dean's Office
B Floor, The Medical School
Queen's Medical Centre
Nottingham NG7 2UH

Who has reviewed the study?
This study has been reviewed and approved by the University of Nottingham Medical School Ethics Committee.

Who should I contact for further information?
If you have any queries please contact:

Penny Benford
(PhD Student)
University of Nottingham
School of Community Health Sciences
ADRU
B Floor, The Medical School
Queens Medical Centre
Nottingham NG7 2UH
Tel: 0115 8230245 **Email**: mcxpb@nottingham.ac.uk

Appendix J

Website information for interview participants

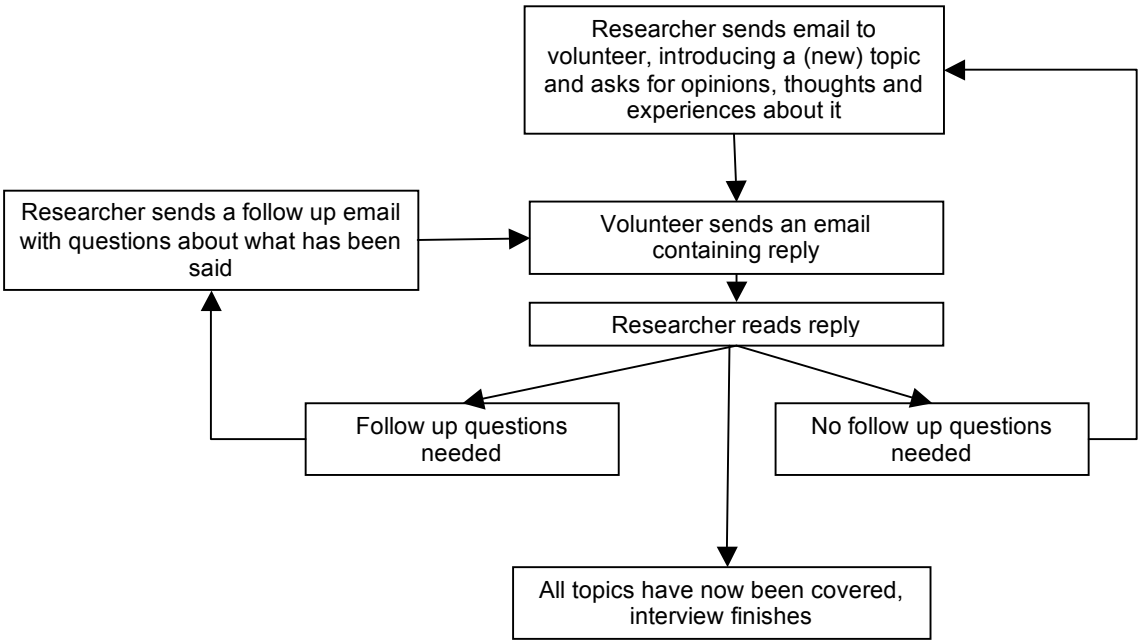
Email interview process

The interviews will carried out by Penny Benford via a separate email address, specific to the project, which you will be given as the process begins.

The interview will begin with an email in which you will be asked about your thoughts, experiences and opinions about one of the topics from the topic guide. When I receive your reply I may feel I need to follow up on what you say with some more questions which I will email back to you. When I receive your reply to those questions, there are two options for my next email: either I may once again follow up with questions about what you have said, or, if it seems we have covered everything I would introduce a new topic and ask for your thoughts, experiences and opinions on that. And so the process would continue. In this way I hope that we will be able to have an online conversation about the relevant aspects of Internet communication.

If there is anything in my emails which is not clear or which you are not happy to discuss please do tell me in your reply.

Because of the occasional unreliability of email, any message not responded to will be re-issued after 7 days in case it has been lost. For this reason it may be a good idea to let me know in advance if you anticipate not being able to reply (eg due to holidays). Similarly I will endeavour to let you know if I am likely to be offline and unable to reply to you.



Broad Topic Areas

Topic 1: Reasons for getting involved in online communication and its effect on your life

Topic 2: The Internet as a communication medium and how it compares to other forms of communication eg face to face, telephone, letters, text

Topic 3: Who do you communicate with online and how do these relationships compare to relationships with people in the real world?

Topic 4 What motivates you to be involved in an Internet based group (eg chat room, bulletin board, newsgroup) or not?

Appendix K

Consent form for interview participants

University of Nottingham, School of Community Health Sciences

Title of Project: A study to explore the experiences, motivations and perceptions of people with Asperger syndrome or high functioning autism who use the Internet for communication

Name of Investigators: Penny Benford, PhD student
Penny Standen, Reader in Health Psychology

Volunteer's Consent Form

Please read the information sheet which explains the aims and procedures of the study. If you agree to take part in the study, please read the following statements and indicate your agreement below.

- I voluntarily agree to take part in this study.
- I confirm that I have read and understood the information sheet (version 1.3) for the study.

1. I have had the opportunity to contact one of the investigators to ask questions and have understood the advice and information given as a result.

- I authorise the investigators to disclose the results of my participation in the study but not my name.
- I understand that information about me recorded during the study will be kept in a secure database. If data is transferred to others it will be made anonymous. Data will be kept for 7 years after the results of this study have been published.
- I understand that I can ask for further instructions or explanations at any time.
- I understand that I am free to withdraw from the study at any time, without having to give a reason for withdrawing.

Do you agree to take part in the above research study?(please answer yes or no)…….

Name: ……

Date: …….

Now please return this form by email to Penny Benford: mcxpb@gwmail.nottingham.ac.uk

(The section below will be completed by the Penny Benford on return)

I confirm that I have sent …… a copy of the information sheet and have been available to answer any questions about the project.

Investigator's Signature: …….. ***Name***: ……

Study Volunteer Number: ……***Date***……..

Appendix L

Letter of ethical approval for interview study

This document is not available

Appendix M

Detailed version of interview topic guide, including suggested prompts

Internet communication and autism topic guide

<u>Topic 1</u>: Reasons for getting using Internet communication, the different ways in which you use it and its effect on your life

1. Please could you tell me about the different ways in which you use the Internet for communication

Prompt: <u>Function</u>: Work, entertainment, hobbies, communication, information…… what else?
<u>Type</u>: email, chat room, instant messaging, newsgroups, bulletin

2. Could you tell me about how you came to try out online communication?

Prompt: How did you hear about it? What attracted you to try it out?

3. Can you tell me about the first time you communicated online?

Prompt: What happened, what did it feel like, what did you think about it, what was your reaction?

4. After that first time what made you want to carry on communicating over the Internet ... or not?

5. In what ways do you think you gain or benefit from Internet communication?

Prompt: What possibilities and opportunities has it created, if any?

6. What are the risks of communicating over the Internet?

<u>Topic 2</u>: The Internet as a communication medium and how it compares to other forms of communication eg face to face, telephone, letters, text

1. What is it about Internet communication which you like?

2. What is it about Internet communication which you don't like?

3. How does communicating over the Internet compare to other types of communication (face to face, letter, telephone, text messaging)?

Prompt: In what ways do they differ?
How are they similar?
Which type(s) do you prefer?

4. How does "live" Internet communication (eg chat rooms, instant messaging) compare with non live (eg email, bulletin boards etc)?

5. What do you think about the following aspects of online communication:

Pace of communication
Being based on text rather than spoken language face to face
Communication via a computer interface
Being anonymous
Use of emoticons and ways of adding expressing
Availability of information to help interaction on line eg rules, netiquette

<u>Topic 3</u>: Who do you communicate with online and how do these relationships compare to relationships with people in the real world?

1 .How does online communication with someone with ASD compare to communication with a neurotypical person?

2. Are your online relationships separate from offline relationships or is there overlap?

3. What do you think about communicating online with someone you have not met face to face?

4. What is it about online communication which makes forming a relationship easier/more difficult?

5. What effect has it had if any on your social contact offline?

6. How do online relationships differ from offline relationships?

Prompt: How strong
How long lasting
A feeling of connection or bond?
Empathy? (definition needed)
Support in times of need
Exchange of ideas and information

7. How does your identity or role online compare to offline?

Prompt: Does it feel different? If so ,in what ways?
Does it feel more or less real or comfortable?

<u>Topic 4</u>: What motivates you to be involved in an Internet based group (eg chat room, bulletin board, newsgroup) or not?

1. What made/did not make you want to get involved?

Prompt: How did you hear about it?
What attracted you to try it?
What made you want/not want to stay involved?

2. Do you feel part of a community?

Prompt: Is there trust? Group identity? Shared interest? Reciprocity? Interconnectivity? Mutual support?

3. How do online communities compare with offline experiences?

4. What do you think about the following aspects of internet groups?

Rules and moderation
Being able to lurk
Being able to look back at archives of group interaction
Knowing there is a shared interest as defined by membership
Netspeak ie particular styles of communicating within the group?

<u>Finishing Question:</u>
What do think is the important message to neurotypical peopleabout internet communication and people with Asperger syndrome/high functioning autism?

Appendix N

Introductory email for interview participants

Dear

A little while ago you returned a form consenting to be interviewed (by email) about your use of the Internet as a communication medium, as part of our research project. I would like to thank you once again for your help with this.

I am sending you this email in the hope we can now proceed with our interview. If for any reason this is not a convenient time to start the interview, please let me know and we can reschedule.

Below is the first topic for you to think about and for you to respond to as you feel appropriate. Please answer with as much or as little as you feel comfortable with. You are free to answer in a few sentences or by longer emails. There is no right or wrong answer. It is your interview and you set the agenda!

Anyway here goes with the first topic:

"Please could you tell me about your reasons for getting involved in online communication, the different ways in which you use it and its effect on your life."

(This is an introductory question, so please do not be put off if the topic seems too huge. Your initial thoughts, even if brief, are welcome and will form a basis on which I can ask more specific follow up questions.)

Please note that for the purposes of the Interview process I am using a separate email address which is:

internetproject@gwmail.nottingham.ac.uk

Also, before replying to this email, you may like to revisit the project website to remind yourself about the process involved in email interviews and the broad topic areas to be covered: http://www.nottingham.ac.uk/~mcxpb/Information/

The website will be available throughout the course of the interview should you want to refer back to it at any time.

I look forward to hearing from you.

Best wishes

Penny Benford

PhD Student
(University of Nottingham)
School of Community Health Sciences
B Floor
Medical School
Queens Medical Centre
Nottingham
NG7 2UH
Tel. 0115 8230245
Fax. 0115 823 0231
(PLEASE NOTE THESE NUMBERS HAVE CHANGED)

Appendix O

Questionnaire sent to pilot email interviewees

Your answers to the following questions would be greatly appreciated, with any comments you would like to make.

1. Did the interview take up too much of your time and/or energy?

2. Was the availability of the webpage(http://www.nottingham.ac.uk/~mcxpb/Information/), which included a guide to the interview in terms of the process and the broad topics to be covered, useful?

3. When responding to your emails during the course of the interview, my emails (containing follow up questions) sometimes included your email, and sometimes did not. Which would you prefer, if any?

4. Did my follow up emails to you come too quickly, or slowly, or did it not matter to you the time taken for me to reply?

5. How easy was it to follow the "direction" or "course" of the interview as it proceeded?

6. Did the types of questions asked seem relevant to the topic of the interview?

7. How could the procedure for conducting these interviews be improved?

8. Anything else you would like to say about the interview?

With thanks and best wishes

Penny